Explore the untapped digital data of neglected tropical disease, and provide insights for stakeholders to take strategic actions.

Master of science thesis for the degree of Strategic Product Design at Technology University of Delft

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Author,
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Abstract

People have been using the digital technology domain to seek solutions to combat neglected tropical diseases. Aside from feasibility and effectiveness, WHO has pointed out the importance of having an overview that pinpoints the lacking infrastructure for scaling up and sustaining digital proposals. This research demystifies the untapped digital data in combating neglected tropical disease and aims to provide an overview for people to take strategic action. Who are all the stakeholders in this elimination procedure? What are the needed data to tackle this disease? How can digital innovation best interfere with the current disease elimination flow?

The researcher has chosen the content of Kanya and the neglected disease of Schistosomiasis as the subject. Building on numerous expert interviews and the literature review, the footprint of disease combating related data has been systematically analyzed from different angles. With a holistic view, this series of analyses poses as a step-by-step guide for the strategic planning of complicated neglected disease or health-related issue in low-resource setting countries. An example of a new Schistosomiasis diagnostic device, SODOS, is presented at the end to showcase the effectiveness of the analyzing approach.

Keywords

Schistosomiasis / Neglected tropical disease / Low resource settings / eHealth / Digital data / Data footprint / Strategic action / Sustainable interventions / Scalable impact / SODOS

Contribution

- The researcher introduced an overview of the untapped digital data for Schistosomiasis. The overview paves the way for future eHealth and mHealth interventions in the field of Schistosomiasis in low-resource settings.

- A set of mapping graphs increases communication between stakeholders in the field of Schistosomiasis, which can be beneficial for future collaboration and partnership.

- Based on the characteristics and pattern of data, the analysis reflects the influence of each data, which could serve as a hint for a digital revolution project that aims to make their move impactful.

- Gaps in the current Schistosomiasis elimination situation is translated into clear directions for proactive improvements approach in the future.

- Based on expert interviews in different levels of healthcare, the research rendered the overview of a complex disease elimination situation, which lay a good foundation for future studies in the field of Schistosomiasis and the health system.

- The research encourages stakeholders in reviewing their daily job from a strategic point of view and gives people with good intention an opportunity in making a sustainable intervention.

- The value of the research is beyond providing developing advice to SODOS. The research set a good example of demystifying the complexity of neglected diseases. Based on the research, similar research can be more easily conducted for diseases like leishmaniasis, trypanosomiasis, hookworm, etc.

- Neglected diseases should not be neglected. By illustrating, color coding, categorizing, leveling, and streamlining, the research gives a solemn and far-distance topic a more digestible entry point. With the style of the research, people outside the field of medical, parasitical, governmental, are all invited to rack their brains and devote their innovation in contributing to the elimination of this disease.

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The approaching new era of Digital Technology!
Neglected tropical disease "Schistosomiasis"

1 Background -
The triggering of this research

AidX Medical B.V. has been devolving to ease the pain of health issue globally with technology by providing solutions to hospital, researcher, and remote areas. Aside from Malaria, one of the main focused diseases of AidX, the company also set foot in the participation of eliminating Schistosomiasis. Schistosomiasis, being one of the deadliest among neglected tropical diseases, Smart Optical Diagnostic Of Schistosomiasis (further referred to as SODOS) is invented. Being sensor-based, automatically functional, able to rapidly upload data to a server, and sensitive to light infectious detection with a relatively cost-effective production price, SODOS is expected to become the substitute for the current field diagnostic method, microcopy egg count.

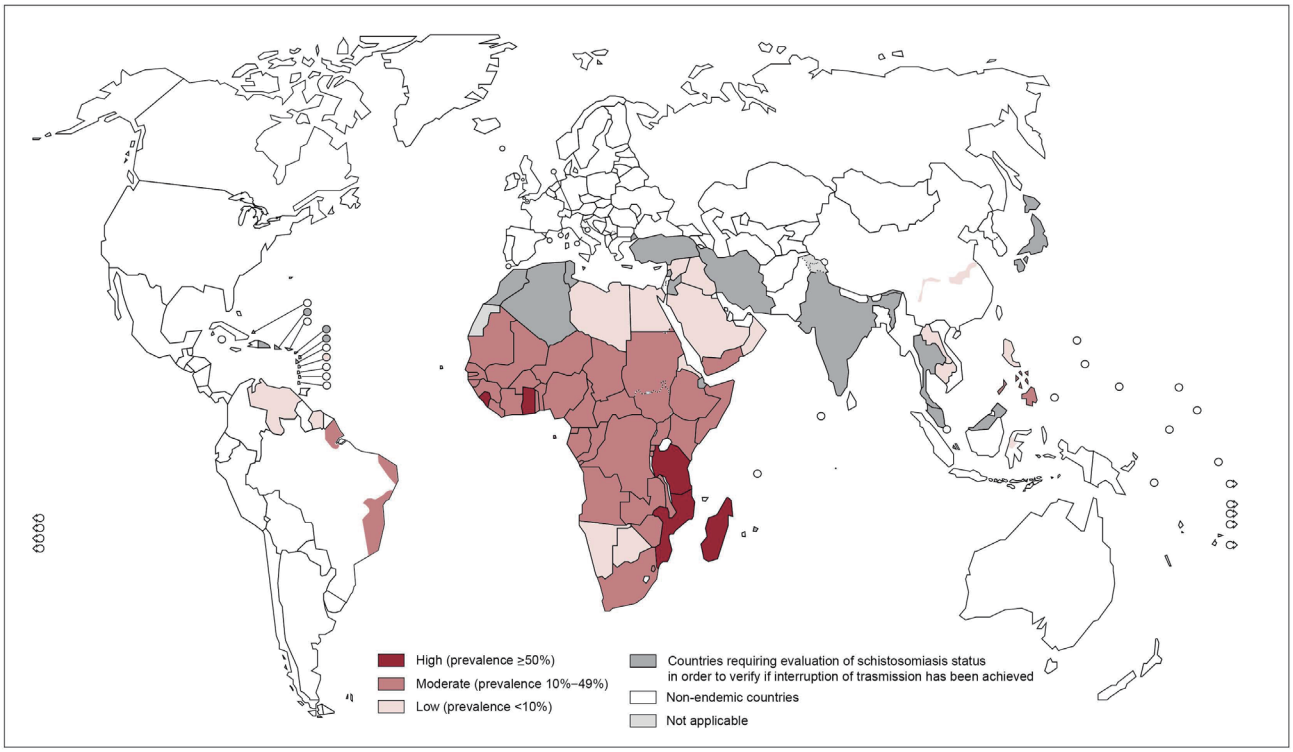
The trend of eHealth is believed to be either incidental or conducive to SODOS's aspirations in easing the pain of 250 million Schistosomiasis patient. The sensor-based operation system gives SODOS the ability to scale up its effectiveness. However, what can be the approach to interfere successfully with the current Schistosomiasis disease elimination procedure? At which elimination phase can SODOS create the most value? To whom can the data generated from SODOS be benefiting? Or the other way around, what data is currently needed in the field but is not provided? Of the data not provide, what data can be generated by SODOS? What data gaps are there in the current Schistosomiasis elimination process? SODOS, being one of the many eHealth devices, what kind of benefits can it be to the world?

With the intention to do good and benefit the world of Schistosomiasis in the digital technology domain, the researcher will use this chapter to dive into the two main factors that triggered the research, Schistosomiasis (factor 1) and digital data (eHealth) (factor 2), for a better understanding before identifying the problem-solving direction.

1.1 Factor 1 -Schistosomiasis: the challenge for mankind

Schistosomiasis, also known as bilharziasis, is caused by parasitic water-borne worms. It is a neglected tropical disease (further referred to as NTD) that infects over 200 million people worldwide, making over 650 million people at risk. (Nour, 2010). The problem with Schistosomiasis can be traced back at least to Ancient Egypt, as Schistosomiasis was diagnosed in a mummy 5000 years old (Deelder, 1990). It is surprising to know such an ancient parasitic disease is still haunting more than two hundred million people even today.

This chapter briefly introduces the background knowledge of the disease Schistosomiasis, the controlling procedure, and the current diagnostic approach to such a disease.


High (prevalence ≥50%)
Moderate (prevalence 10%–49%)
Low (prevalence <10%)
Countries requiring evaluation of schistosomiasis status in order to verify if interruption of trasmission has been achieved
Non-endemic countries
Not applicable

The boundaries and names shown and the designations used on this map do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement. © WHO 2012. All rights reserved

Data Source: World Health Organization
Map Production: Control of Neglected Tropical Diseases (NTD)
World Health Organization

World Health Organization

Figure 1-1: Worldwide geographical distribution of schistosomiasis in 2010 (WHO, 2013). More than 207 million people are actively infected by schistosomal globally. (King, 2009)

1.1.1 Disease: Schistosomiasis haematobium

Schistosomiasis is an acute and chronic disease caused by parasitic blood flukes: Schistosoma. While the eradication and control have been successfully seen in some countries, the disease Schistosomiasis is still considered a public health challenge mostly in economic developing tropical countries. (Bonds, 2012) (see figure 1-1)

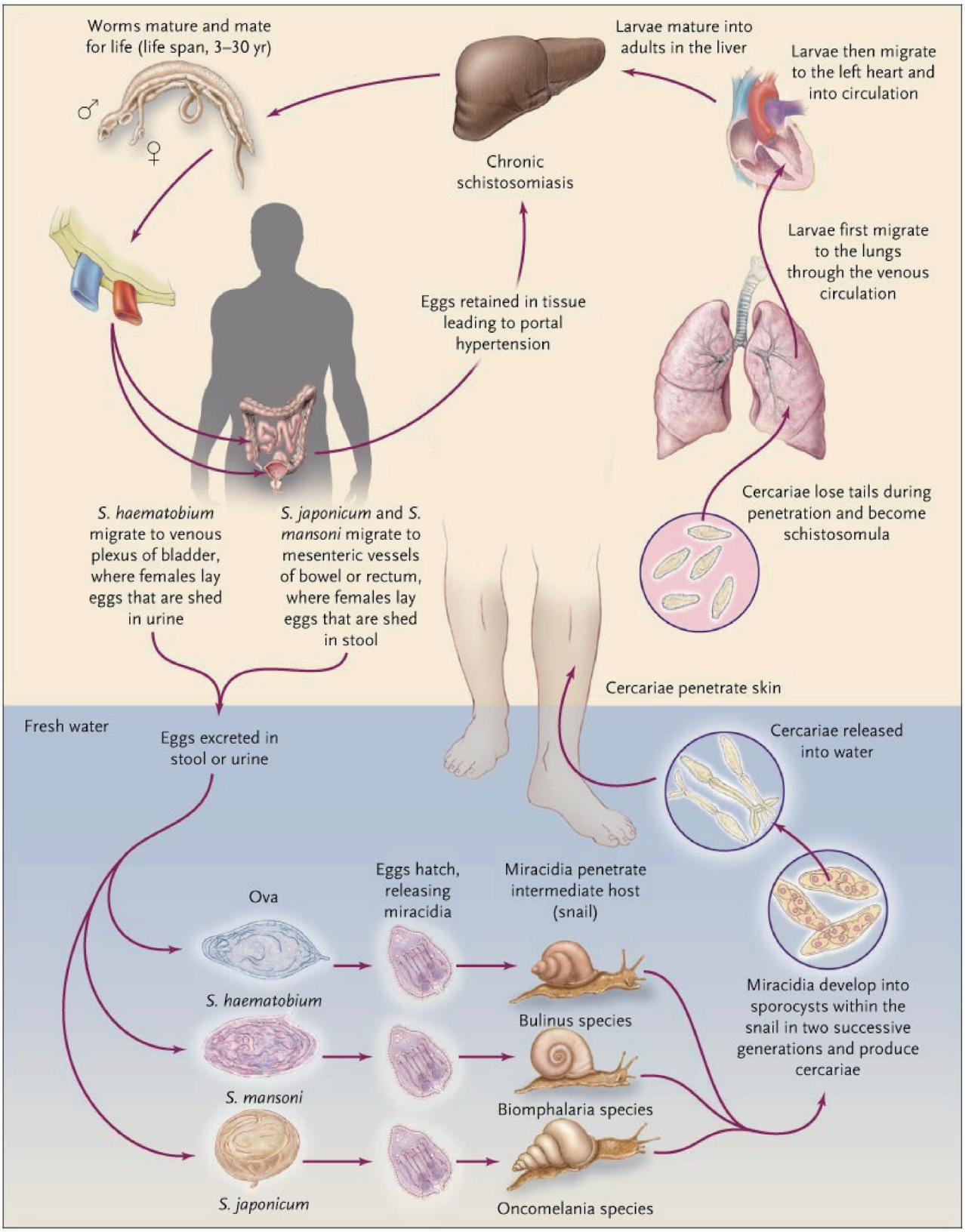
Contact with inadequate hygiene and Schistosomiasis contaminate freshwater expose people to the risk of infection. Via freshwater snails, Schistosomes larval forms of the parasite can penetrate the skin and enter the human body during contact with infested water. The larvae develop into adult worms inside the blood vessels of the infected person, where the females release eggs. These eggs can be either trapped in body tissue, causing the immune response of one's body and leading to organ damage, or being released outside the human body via feces or urine in freshwater, which allows the egg to hatch and continue the parasite's life cycle. (see figure 1-2)

Due to the infectious agents of freshwater, snail host, and human host, the unique schistosomal life cycle can limit endemic areas to certain (sub)tropical zones where humans perform aquatic activities (Medscape, n.d.). A common source of the disease can be freshwater lakes, streams, reservoirs, and irrigation systems. People with the occupation that bring them in contact with infected water in these endemic areas, such as fishermen, farmers, irrigation workers, and domestic tasks workers are considered as high-risk target group (WHO). Water resource engineering and the migration of infected populations can also stimulate the geographic spread.

1.1.2 Current disease ending approach

Based on the principles of preventive chemotherapy-- mass drug administration, (further referred to as MDA) with praziquantel was developed in the 1970s. It has become the "gold standard approach" to control Schistosomiasis since 2002 (Gryseels, 2013). Inexpensive drug treatment was offered to the entire target group (school-age children and high-risk adults) without an individual diagnosis (WHO, 2006) and irrespective of infection status individually (WHO, 2011). High-coverage MDA in endemic areas is aimed to alleviate symptoms by killing adult worms and reduce transmission, to ease disease burden in a low-resource setting countries with limited access to medical health (Webster, 2014). With the intention of "leaving no one behind," universal health coverage came to be a crucial component.

According to the current WHO guidelines, prevalence (the percentage of individuals in a population who are infected) is the key indicator for the selection of control


Worms mature and mate for life (life span, 3–30 yr)
♂
♀
Chronic schistosomiasis
Larvae mature into adults in the liver
Larvae then migrate to the left heart and into circulation
Larvae first migrate to the lungs through the venous circulation
Cercariae lose tails during penetration and become schistosomula
Eggs retained in tissue leading to portal hypertension
S. haematobium migrate to venous plexus of bladder, where females lay eggs that are shed in urine
S. japonicum and S. mansoni migrate to mesenteric vessels of bowel or rectum, where females lay eggs that are shed in stool
Cercariae penetrate skin
Fresh water
Eggs excreted in stool or urine
Cercariae released into water
Ova
Eggs hatch, releasing miracidia
Miracidia penetrate intermediate host (snail)
S. haematobium
Bulinus species
S. mansoni
Biomphalaria species
S. japonicum
Oncomelania species
Miracidia develop into sporocysts within the snail in two successive generations and produce cercariae

From The New England Journal of Medicine: Ross AG, Bartley PB, Sleigh AC, et al. Schistosomiasis. 2002;346(16):1212–1220.

Figure 1-2: The life cycle of Schistosoma species (Ross, 2002).

strategy (WHO, 2011)(see table 1-3). Prevalence can be collected through survey and sample diagnosis in the field. In other words, the result of survey testing via a group of representative will determine how the entire group takes the MDA.

Category	Baseline prevalence	Action
High-risk	> 50%	MDA once a year (include adults at risk)
Moderate-risk	10-50%	MDA once every two years (include adults at risk)
Low-risk	< 10%	MDA twice during primary schooling age

Table 1-3: Frequency of MDA in target populations (WHO, 2013)

School-age children are the most vulnerable target group, due to undergoing intense periods of physical growth, as being infected with schistosomiasis can affect growth and diminish learning capability. School-age children are thus seen as the primary target group undergoing survey testing when determining illness prevalence. It is also easier to target school-aged children with efficiency through the educational system as school infrastructure reduces cost and poses as a good opportunity for the education of personal hygiene awareness. School-aged children are the most important high-risk group for schistosomiasis (WHO, 2011). The drug coverage of school-aged children in an endemic area is an important indicator in goal achievement according to the WHO guidelines. The elimination goal for 2020 is to successfully treat at least 75% of school-aged children (WHO, 2011).

Repeated treatment is necessary through MDA to tackle re-infection of the disease. A sustainable MDA intervention can take five years or more, depending on the funding and elimination strategy in different countries. Ideally, the complete intervention will show the declining in prevalence every time the survey is conducted (see figure 1-4).

The drug used in the African region is mainly through the Praziquantel Donation Program of Merck KGaA, via the World Health Organization (Pediatric praziquantel consortium). The locally produced drug is, however, the best option, as it can reduce cost in transportation, avoid possible delays in the invoice, and can potentially stimulate the local economy (WHO, 2011).

Survey Prevalence, %	Baseline	Midterm	Endline	Relative Reduction (Baseline – Endline)
STH Combined	33.6	18.6	15.2	54.9 (p<0.001)
Hookworm	15.2	2.4	1.3	91.6 (p<0.001)
A. lumbricoides	20.7	13.8	11.1	46.7 (p<0.001)
T. trichiura	6.3	5.0	4.6	27.8 (p<0.001)
S. mansoni	2.4	1.7	2.0	19.4 (p=0.061)
S. haematobium	18.0	7.9	3.9	78.2 (p=0.001)
Average Intensity, epg				
STH Combined	2012	1141	1088	45.9 (p<0.001)
Hookworm	62	9	11	82.9 (p<0.001)
A. lumbricoides	1914	1113	1059	44.7 (p<0.001)
T. trichiura	36	19	18	50.1 (p<0.001)
S. mansoni	14	6	5	61.7 (p=0.002)
S. haematobium	20	7	4	81.4 (p=0.011)

FIgure 1-4: example of declining in prevalence: Baseline (done at the first year of MDA), midterm (done at the third year of MDA), and end-line (done at the last year of MDA) prevalence (%) among Kenyan school children, 2012-2017. (KEMRI)

1.1.3 Diagnostic

Microscopic egg count is currently the standard approach to diagnose Schistosomiasis (Gryseels, 2006). By distinguishing the shape of the unique Schistosoma eggs (see images 1-5), the technician can make a diagnosis, and tell whether a patient is infected with schistosomiasis.

According to the type of Schistosoma species, the egg can be either in the stool (intestinal schistosomiasis) or urine (urogenital schistosomiasis) of the patient. The following report is going to focus mainly on urogenital schistosomiasis.

Images 1-5: the egg of Schistosoma under the microscope. Schistosoma eggs can be recognized by the oval shape and the terminal spine at the end. Left: egg detected for Schistosomiasis Haematobium. Right: egg detected for Schistosomiasis Mansoni. (YourGenome, n.a.)

Urine filtration and centrifugation are processed to capture eggs before conducting the microscopic examination for eggs counting. The infected situation can be determined based on the number of eggs in the fixed amount of urine (10ml). More than 50 eggs per 10 ml of urine are considered a heavy infection (Oluwasogo, 2013). However, it is easy to misdiagnose light infection (King, 2010)(see figure 1-6), as the egg count is done manually with the naked eye through the microscope (Amoah, 2018). Heavy cases can also be misdiagnosed due to human error in counting, causing false-negative (Bustinduy, 2014).

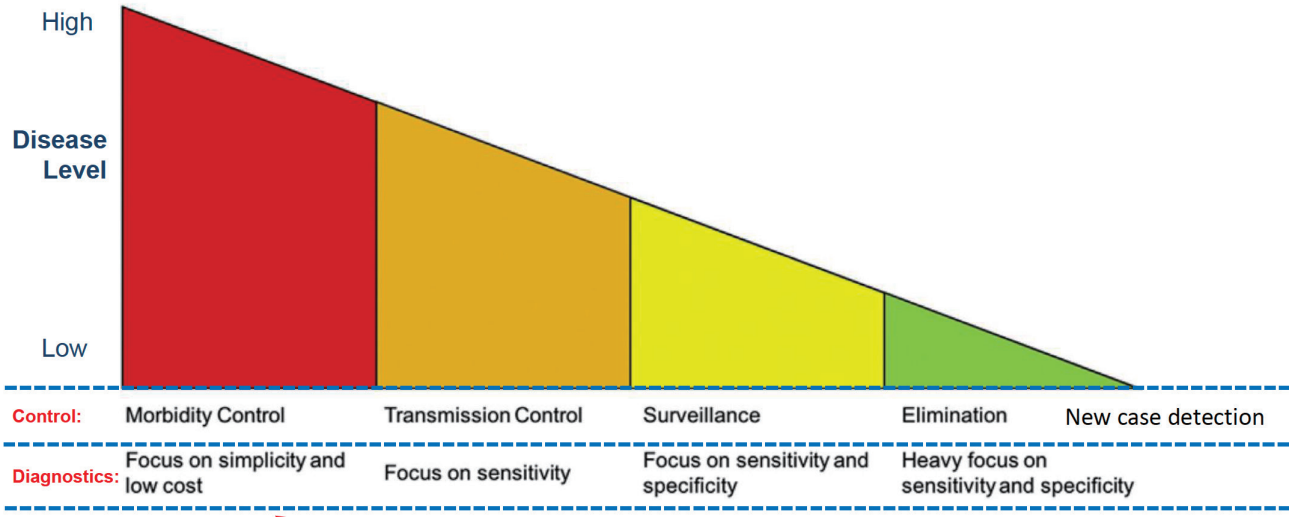


Figure 1-6: The relationship between disease control and diagnostic (Le, 2017). The lighter the disease level is, the more sensitive and specific diagnostic has to be. The commonly used approach for MDA, microscopic egg count, can easily misdiagnose light infection.

1.1.4 Drawbacks and countermeasures

"Control" is one of the most important steps to tackle this neglected disease. However, due to the complexity of disease causes, it can be hard to grasp every piece of information. One main problem, for example, is the difficulty in keeping track of the real drug adherence via MDA either school-based or community-based. According to the current MDA goal pledged by WHO, countries are urged to reach 75% drug coverage of school-aged children. However, studies have shown that the amount of drug reported as

given may not be the same as the number of drugs swallowed (Shuford, 2016). A variety of factors can result in this inadequate control of non-adherence to MDA drugs, such as the accessibility of treatment, the relationship between drug distributors and the citizens, and the low awareness of MDA drug benefits (Krentel, 2013). These persistent non-adherers pose as a loophole in the disease elimination process, as the infected non-adherers continuing carries the Schistosoma parasite, and can release the eggs back into the environment (Farrell, 2017).

The lack of control in treatment adherence will hinder the eradication of Schistosomiasis and stimulate reinfections (Toor, 2018). The issue of treatment coverage may be greatly improved by taking into consideration social-behavioral factors when designing the MDA procedure (Krentel, 2013), as well as including individual treatment data that record longitudinal patterns of compliance during MDA (Farrell, 2017), instead of only recording the overall coverage.

1.1.5 Involving technology

Location of water bodies, residential population, disease prevalence, resource deployment, and diagnostic methods are all variabilities that can influence the controlling of this troublesome disease. The controlling of these disease-related variables are important factors in making forecasts. The data of these variables have the potential to transform into innovation. To have better risk management and change controls, WHO has set up a databank for neglected tropical disease, including Schistosomiasis, for the world to have a better glance about the endemic countries list and their disease severity (see image 1-7) (WHO). Dr. Lalaye in Chad has been looking into mobile device usage, expecting to improve the detection of early Schistosomiasis infection (Reach for change). Disease Data Management System in the UK is exploiting the integration or data to assist malaria and dengue control (LSTM); Data Zetu in Tanzania strives to promote evidence-based decisions to improve people's health (Data Zetu, 2018).

Schistosomiasis, this neglected tropical disease that has been haunting people for more than a thousand years, is aimed to be eliminated as a public health problem globally by 2025 as stated in WHO's strategic roadmap (WHO, 2011). Luckily, the comprehensive and macroscopic medical development has given humans the chance to take better control over this neglected disease by leveraging the help of digital technology (PATH).

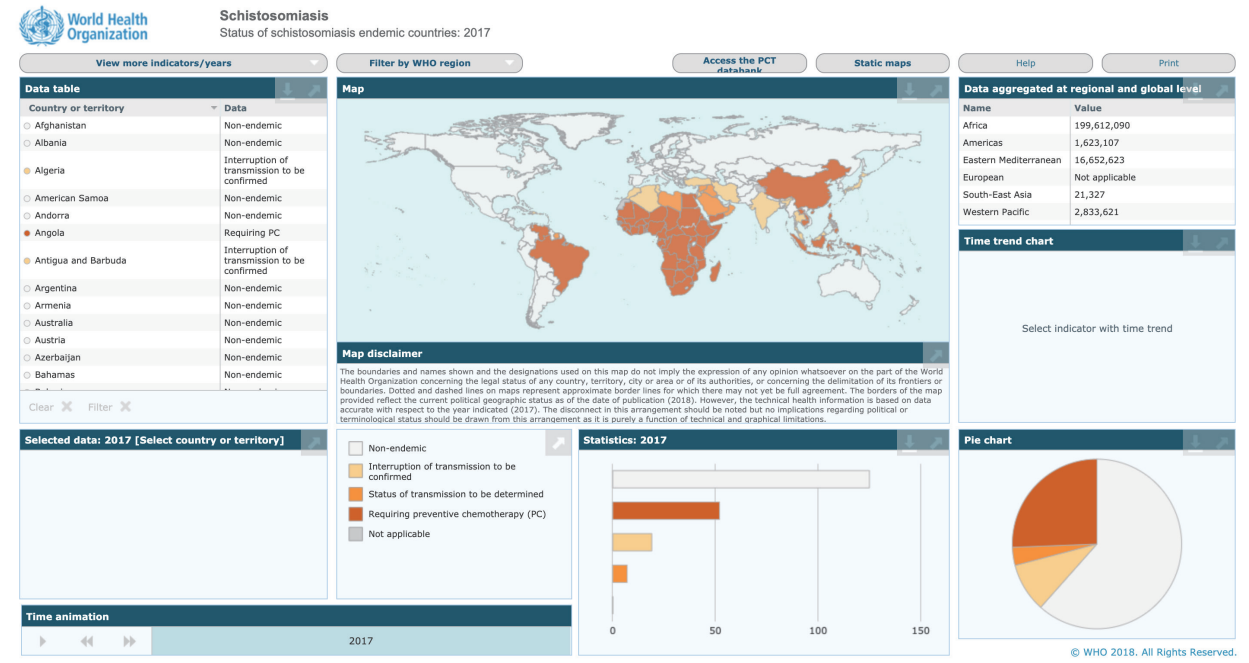

World Health Organization
Schistosomiasis
Status of schistosomiasis endemic countries: 2017
View more indicators/years
Filter by WHO region
Access the PCT databank
Static maps
Help
Print
Data table
Country or territory
Data
Afghanistan Non-endemic
Albania Non-endemic
Algeria Interruption of transmission to be confirmed
American Samoa Non-endemic
Andorra Non-endemic
Angola Requiring PC
Antigua and Barbuda Interruption of transmission to be confirmed
Argentina Non-endemic
Armenia Non-endemic
Australia Non-endemic
Austria Non-endemic
Azerbaijan Non-endemic
Bahamas Non-endemic
Clear
Filter
Map
Map disclaimer
The boundaries and names shown and the designations used on this map do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement. The borders of the map provided reflect the current political geographic status as of the date of publication (2018). However, the technical health information is based on data accurate with respect to the year indicated (2017). The disconnect in this arrangement should be noted but no implications regarding political or terminological status should be drawn from this arrangement as it is purely a function of technical and graphical limitations.
Data aggregated at regional and global level
Name
Value
Africa 199,612,090
Americas 1,623,107
Eastern Mediterranean 16,652,623
European Not applicable
South-East Asia 21,327
Western Pacific 2,833,621
Time trend chart
Select indicator with time trend
Selected data: 2017 [Select country or territory]
Non-endemic
Interruption of transmission to be confirmed
Status of transmission to be determined
Requiring preventive chemotherapy (PC)
Not applicable
Statistics: 2017
0
50
100
150
Pie chart
Time animation
2017
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Image 1-7: Schistosomiasis database from WHO. This is the print screen of the webpage made in August 2019; the data remains in the year 2017. To a certain extent, this fact reflects the lack of promptness in the information.

1.2 Factor 2 - Digital health: the opportunity to optimize solutions

De Montjoye (2014) described data as the oil of the digital economy. Compared to electronic data, digital data are "alive; from a mobile banking application that shows people their money spending behavior to the electronic boarding passes that automatically routes passenger to the rescheduled plane when something is changed, digital data has the ability of rapid synchronization. This characteristic of digital data equipped people with the power to react to changes transforms how people work (Marsh, 2018), and changes the definition people give to "taken-for-granted."

The analytical power of computers, the popularity of the Internet, declining cost of data storage, and the development in digital technology are creating new data and tools at an unprecedented scale in the African country (Africa data revolution report, 2016). A revolution in data collection can tap into a new type of information sources and therefore creating new opportunity to optimize current working approaches for analysis and monitoring (Africa data revolution report, 2016). The vision of improving the way of living through digital data is also mentioned in WHO's report (WHO, 2015).

1.2.1 Digital data in Healthcare

Benefiting from the convenience of visibility and the feeling of being in control, this infection point for digital transformation is happening across different industries (Mehta, 2018). People start imagining the world of advantage with the opportunities in the digital age. The industry of healthcare, with large amounts of data historically generated due to record-keeping, compliance requirements, and patient care (Raghupathi, 2010), is also undergoing a global transformation. Aside from the characteristic of volume, what is even more challenging for the healthcare industry is the management of the diverse data types and speed in transferring (Frost, 2015). Today, most healthcare data are still stored in a traditionally static form such as paper files, x-ray films, and scripts. The transformation of digital data in the healthcare sector also requires the correspondence of data acquisition and transferring system, which includes software, hardware, and management method (Frost, 2015).

eHealth and mHealth

Luckily, smartphones with wireless connectivity and built-in sensors pose as a new and cost-effective opportunity to capture and handle health-related data (Perkel, 2017). Such a trend can be seen in the increasing usage of electronic medical records (EMRs), healthcare information systems (HIS), and wearable smart devices (Mehta, 2018). The

Images 1-8: mHealth and eHealth allows a patient to be diagnosed with nearly no limitations of space or time. Photo credit: left image: © 2019 Apple Inc / right image: © 2019 Video telemedicine)

phenomenon of communicating health information and action though technologies are also understood as eHealth (electronic health), and more precisely as mHealth (mobile health) when it is supported by mobile devices, personal digital assistants, or wireless devices (Ali, 2016). Instead of the low barrier in owning health-data-capturing devices, eHealth and mHealth also reduces the workload and errors of paper documentation, simplify diagnosis procedure, and assist monitoring for data-gathering (Haque, 2017)

Goals of universal health coverage (UHC) stated that all people should have access to health services they need, irrespective of socioeconomic status, and financial hardship (Mefl, 2014). The 4.7 billion mobile phone users globally across the developed or developing world indicates the opportunity to achieve this global wellness. By harnessing the basic ability of mobile functions like voice recording, video capturing, and image storage, the effectiveness of health can be delivered to the farthest reaches of the globe (mHealth Alliance).

By associating digital data patterns from these health devices and understanding trends of user behavior on a mass scale (Raghupathi, 2014), these volumes of complex and linkable information (NIH, 2014), can be considered as an indicator for hypothesis-generating (Khoury, 2014). Aside from volume, a large amount of digital data provides velocity, variety, veracity, and value (also known as the 5 Vs of big data) (Demchenko, 2014), the ubiquity of digital health data is able to support clinical decisions, enhance measurement and accountability, and strengthen the coverage of life-saving interventions

Image 1-9: m-Pesa, an example of a revolutionized mobile payment system in Kenya. Photo credit: © n.a. Daily Nation

(WHO, 2015). For health provider and policymaker, digital health data can assist the integration of different health caring elements via information sharing, improving treatment adherence by supporting patient self-management, and improving the quality of decision making with an evidence-based approach (Barbabella, 2017).

1.2.2 Digital data in low resource setting countries

It can be surprising to realize that in low resource setting countries, mobile phones arIt can be surprising to realize that in low-resource setting countries, mobile phones are the cheapest option for communication in terms of speed when there is a distance between people. Fixed-line phones and broadband internet are much more expensive, as telecom infrastructure can be mostly underdeveloped (Etzo, 2010). Mobile phones are commonly used to do money transfers (M-Pesa in Kenya)(see image 1-9), election monitoring (Nigerian election in 2007), and public message delivering (Text to Change project in Uganda) from slums to remote villages. Jagun (2007) posited that the positive influences of these digital services could be grouped into two categories: incremental (speed and efficiency to what they are already doing) and transformational (for creating new opportunity ever in the history). Also, there are production benefits (the device itself and its related service) (Jagun, 2007).

The digitalization transformation in the daily life of low-resource settings countries is also influencing health and medical. The implementation of mHealth and eHealth has surged along with the popularity of mobile devices throughout low-resource settings countries since the early 2000s (WHO, 2015). eHealth is used to collect health

Image 1-10: A community health worker in Tanzania using a mobile application to provide family planning service. (Debra, 2017). Photo credit: ©2015 Ueli Litscher, Courtesy of Photoshare

data, support treatment, and disseminate health education. For example, in Uganda, daily medication reminders will be sent to tuberculosis patients via text message; awareness quizzes for HIV are also sent via digital devices (mHealth Alliance) (Consulting, 2009).

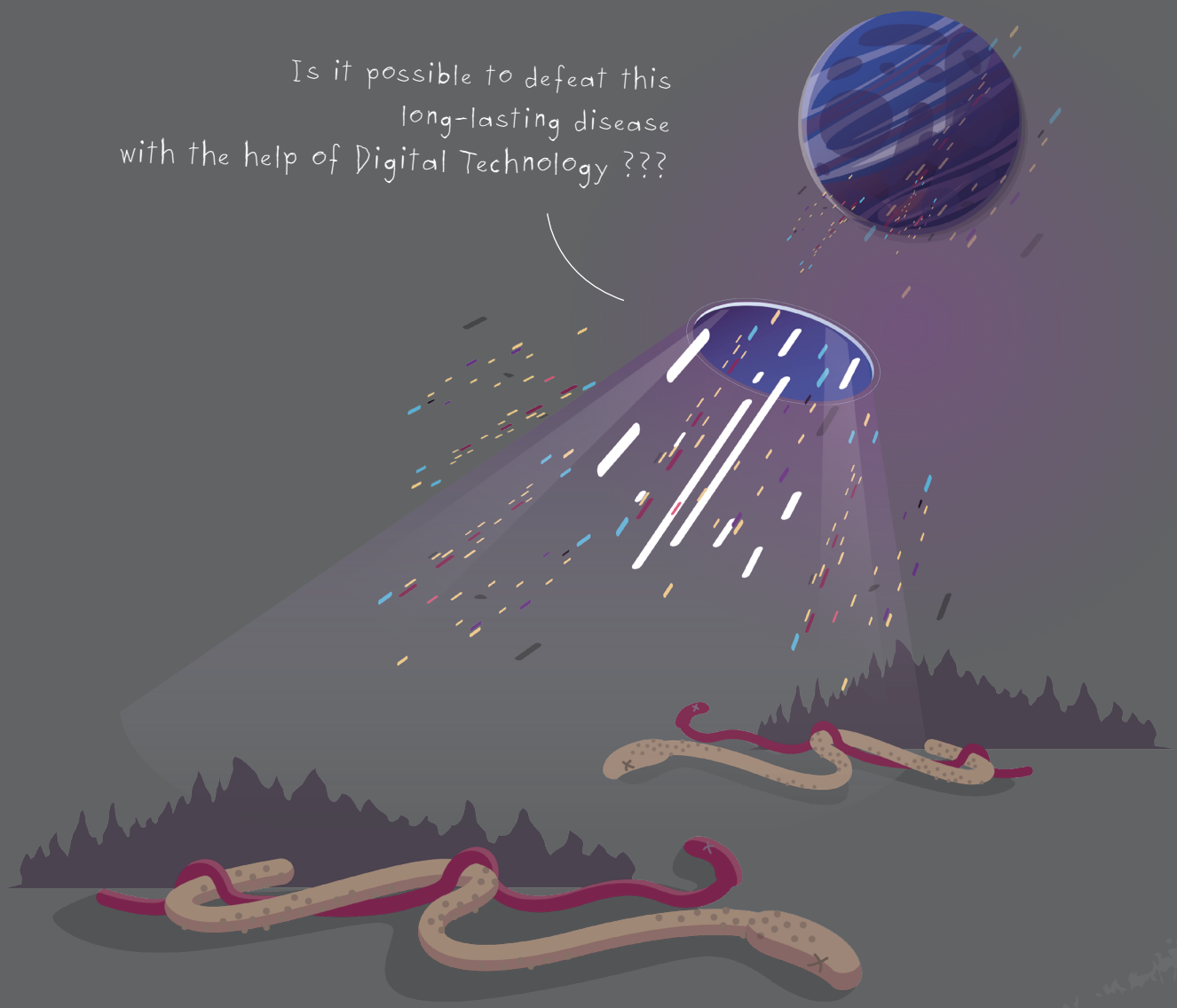
However, while Internet access has become widely available and smartphone usage has been penetrating faster than ever in African countries (Qelp, 2019), the shifting of smooth, linear and longitudinal digitalization in data usage is still considered rare in developing-countries when compared to developed-countries (Purkayastha, 2013). Thus the "digital divide" (Barzilai, 2003' Cullen, 2001; Hoffman, 1998) of industries should not only be understood as a simplistic notion of "technology limitation but also a multi-layered issue, including the ability to access, exploit, and operating information communications technology (further referred to as ICT) (Wei, 2011) (see figure 1-11).

<table>
<tr><td></td><td colspan="5">IT adoption stage</td></tr>
<tr><td>Individual
Organization
Globe</td><td>Digital access divide</td><td>→</td><td>Digital capability divide</td><td>→</td><td>Digital outcome divide</td></tr>
</table>

Figure 1-11: The Three-Level digital divide framework. The usage of digital information is framed into three stages: first, the gap between taking ICT as an opportunity to process their activity; second, the ability to make use of accessible technology; and third, to exploit the result from the previous step into practical outcome. (Wei et al., 2011)

1.2.3 Digital data for neglected tropical disease

For disease surveillance, there is often urgent requirements to detect and intervene at a rapid pace. Diagnostic and monitor can be key to clinical management, especially for infectious disease, as it can be transmitted to others if action is not taken in time (Fallah, 2017). Compared to other diseases that can be easily spotted by symptoms or patients' medical records, governing neglected tropical disease such as Schistosomiasis, in which the characteristics of the disease may obscure factors for digital data collection (Walz, 2015), level-up the challenge of monitoring. Take Schistosomiasis as an example, data collection for tracking disease epidemic area may substantially reflect the biometric trait of the parasite, living habits of snails, or behavior of humans; however, these data still falls short of setting up risk profiling for Schistosomiasis prevention and control. The characteristics of each neglected disease, as well as its complexity in the cause, increase the difficulties in digitalizing the controlling procedure (Walz, 2015).


Is it possible to defeat this
long-lasting disease
with the help of Digital Technology ???

2 Opportunity and methodology

For the disease Schistosomiasis, the golden guideline has been set by WHO to optimize procedures for ending Schistosomiasis; however, local people living in the disease prevalent areas are still coping with limited resources when performing the controlling program.

For digital health data, even though people started to take the convenience of digital data as granted, the usage of digital health data is still strongly dependent on infrastructure (including data management system), the connected chain interaction that comes after the data is gathered, and the "digital divide" mentioned in chapter 1.2.2. The digital divide, however, is an even more challenging when it comes to infectious disease, not to mention the situation of neglected infectious disease.

If having a grip on digital data gives people the feeling of transparency and security in terms of control, it is an irony that, for the deadliest disease that can cause chronic pain, there is not a mature digital data collecting tool that can make people feel in control, let alone having an overview in knowing where to act.

2.1 Problem definition - the digital data of Schistosomiasis

"Sensing" the opportunity of digital data for ending Schistosomiasis is not enough and cannot be useful, as people do not have sufficient information to take the correct action to make their impact sustainable within the whole elimination system. Health interventions via mHealth have been focusing on feasibility and effective, instead of elaborating on the overview, which pinpoints the lacking of specific infrastructure for scaling up and sustaining the digital proposal (WHO, 2015). There is a limited understanding of what is needed to translate these good intentions into larger-scaled long-term practical planning. Therefore, before further examining how data can assist the elimination of Schistosomiasis digitally, it is necessary to take a step back and look at how and what data is generated in the Schistosomiasis' disease controlling procedure.

To further find out what can accelerate bringing people and digital data together to combat Schistosomiasis, the researcher is going to demystify the elimination procedure. The researcher aims to discover the untapped opportunities of digital data.

Research topic

Explore the untapped digital data of neglected tropical disease (NTD), and provide insights for stakeholders to take strategic actions.

Goal of the project (deliverables)

1. Demystify the footprints of data within Schistosomiasis' elimination procedure.
2. Streamline the complex situation to facilitate and encourage people in strategically making sustainable interventions.

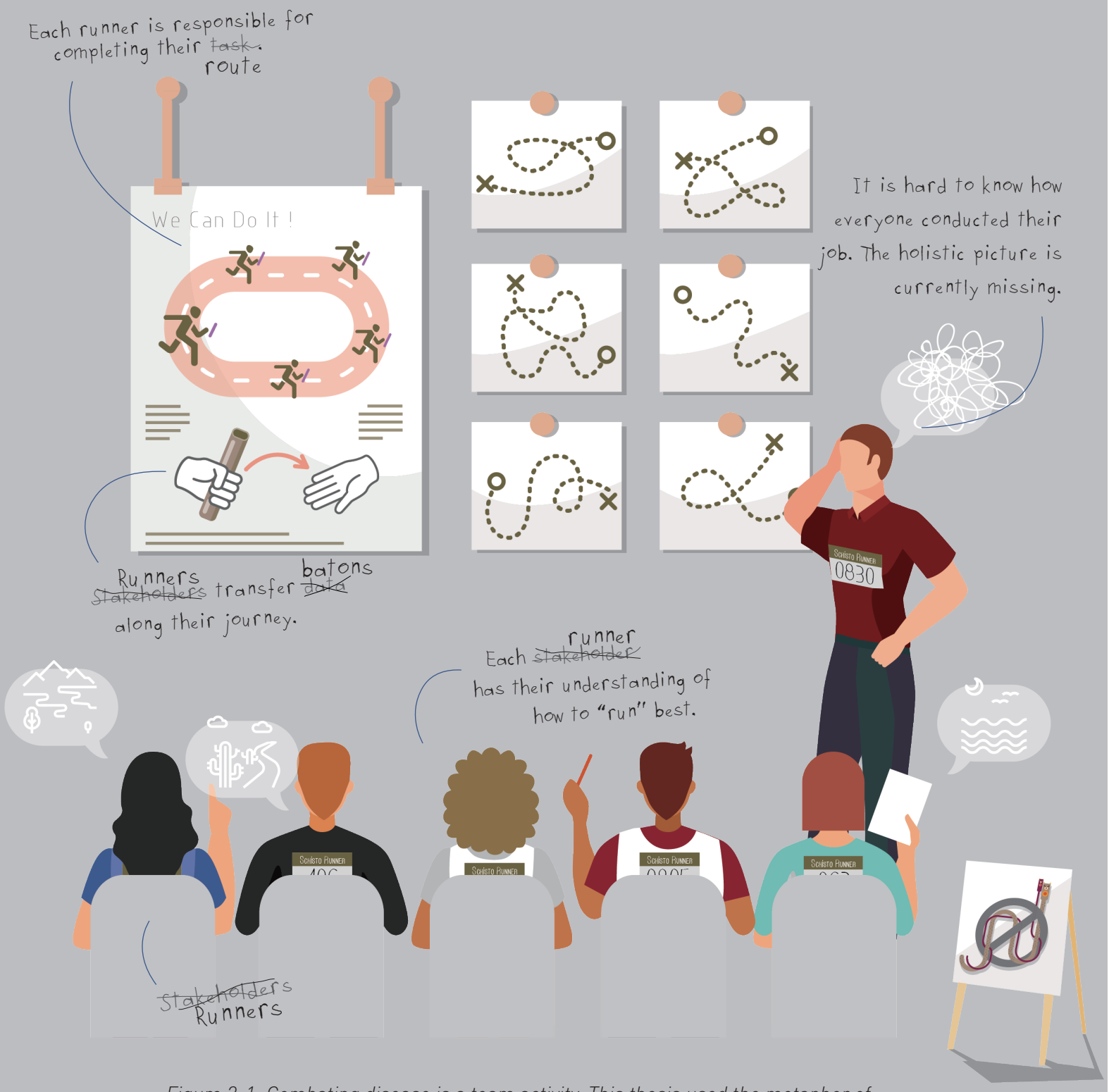

Each runner is responsible for completing their ~~task~~. route
We Can Do It !
Runners ~~Stakeholders~~ transfer batons ~~data~~ along their journey.
It is hard to know how everyone conducted their job. The holistic picture is currently missing.
Each ~~stakeholder~~ runner has their understanding of how to "run" best.
~~Stakeholders~~ Runners
Schisto Runner
0830

Figure 2-1: Combating disease is a team activity. This thesis used the metaphor of a "relay race running" to describe the disease eliminating procedure. Stakeholders are described as runners in the game; data are described as relay-batons; the overview is described as the running track. See chapter 2.2 for further explanation of this method.

2.2 Research methodology

Dedicated to providing insights to all stakeholders involved in the combating of Schistosomiasis, the research falls under the "*base of the pyramid (BoP)*" perspective (see figure 2-2), which takes into consideration the accessibility, availability, acceptability, and sustainability (Prahalad, 2009).

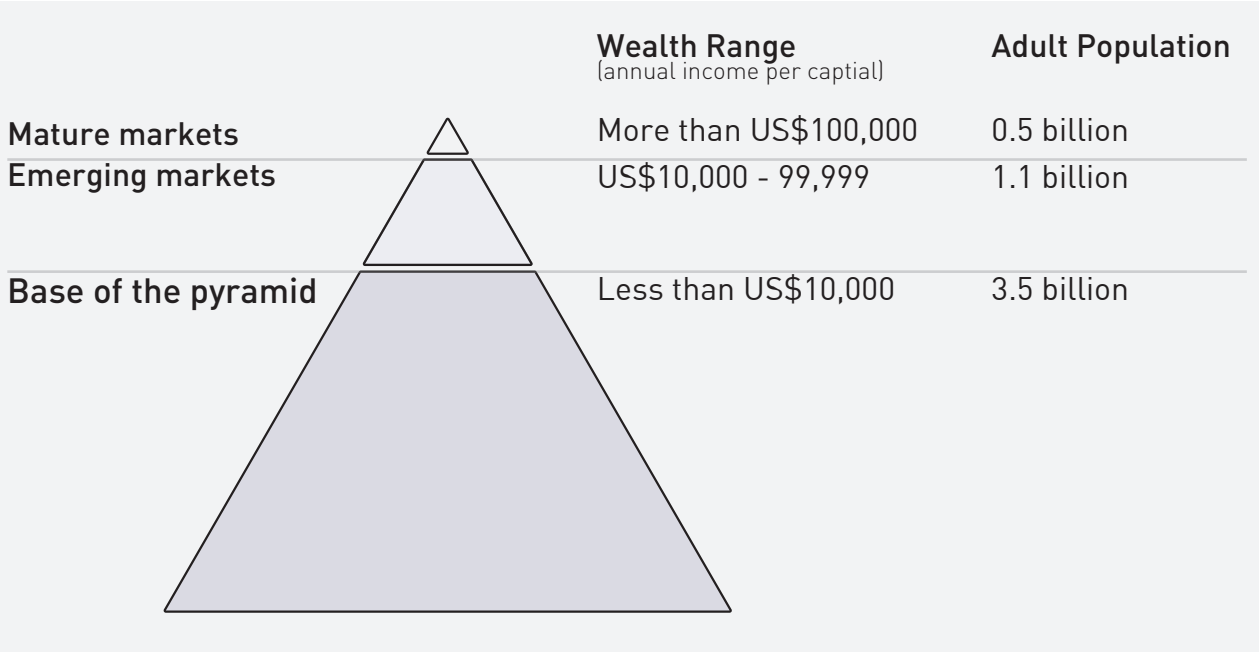


Figure 2-2: the economic pyramid. (Credit suisse global wealth report, 2017)

As an "outsider" of the endemic area; the researcher conducted two-week *field research* in Kenya to have a closer knowledge of cultural background and context. Through meeting local stakeholders, an "insider" perspective is taken into account to understand further otherness. The researcher expected to avoid biases when dealing with all kinds of factors.

The following are the main methods used in the research:

Analogies & Metaphors

Analogies and metaphors are used to help see the complex disease elimination issue in the lens of another domain to support the direction of exploration (Hay, 2008). Starting from the identifcation of the topic, the metaphor of “relay-race running" runs through the whole research (see page 21, 28, 42, 52, 66). This method may not directly help to solve the practical problem of Schistosomiasis digital data usage, but can, to a certain extent, represent how the ideal result can evoke, as well as help convey the idea more easily to the reader. To best convey the idea of this research, the researcher creates an animation with the analogies and metaphors. Scan the QR code on the corner to view the animation.

Bipolarity axis

The method of bipolarity axis is used in the analysis of stakeholder motivations in chapter 3.1 and the diagnostic method discussion in chapter 6.3. With each axis representing noteworthy subjects, different units (stakeholders and diagnostic method) are able to start the joint comparison more easily. The method of bipolarity helps filter out noise during the discussion, as it reveals the most salient subject, and also reflects the missing quality among all subjects (Van der Vorst, 2017).

Expert Interview

Interviews play a decisive role in the research in framing the structure of the Schistosomiasis elimination process. Asmentioned previously, as an “outsider” to the disease elimination content, the interview vividly portrays the problem of the “insider,” and aided in explaining the existing phenomenon, reflects the preference of the world, and help obtain deeper insights for the issue (Byrne, 2001). The method of interview is also used in the ending, chapter 7.1, as validation for collecting feedback of this research approach. Interview guides are prepared before the interview. If necessary, sensitizing documents are sent a few days before the interview. Transcription of the interview will be made and analyzed during the evaluation phase (see Appendix C for interview guides and notes).

Pattern Matching

Through documentation the qualitative interview results and literature reviews, pattern matching is used in chapter 4.3 to form insights from the the research. Predicted theoretical pattern (patterns that are theoretically reasonable) will be matched with observed empirical patterns (patterns that are verified via field research), which helps further confirm any externalized assumptions made previously (Sinkovics, 2018). With the help of graphs, readers are also able to profoundly "witness" the conclusion.

Problem definition

The definition of the problem is used in chapter 5.3 to conclude the analysis phase of the complex Schistosomiasis elimination data researcher procedure. Four problem definitions are carried out in this explorative research. The problem definition is contained in the dissatisfaction in the current situation (in the first half of the definition sentence) and the hint given to the desirable situation (in the second half of the definition sentence). The problem definition does not solve the problem, however, it describes the desired situation and direction (Roozenbury, 1995).

WWWWWH

The WWWWWH (Who, What, Where, When, Why, How) method is used as a checklist in chapter 5.4 to make sure all aspects are clearly covered in understanding the facts and value. This method also systematically addressed the challenge of adopting digital data in the current Schistosomiasis elimination procedure, aiming to direct future researchers in formulating their "task-to-solve" (Tassoul, 2005).

Personas

The method of persona is used in chapter 6.3. In the research, the personas are used to define potential target stakeholders for SODOS. Through the persona, the intended target stakeholder will be richly characterized, as if a real person. The goal of the life cycle (business) can be achieved through personas, which help shape the subject stakeholder into a more tangible target, as well as some major value and needs (Pruitt, 2010).

Find the timing for using these methodologies in the timeline of approach in figure 2-3.

2.3 Research approach

To discover the untapped development potential of digital data in the complicated situation of Schistosomiasis, the research frames the preliminary outline of the elimination structure. In total, 10 hours of interviews with eight interviewees in the field across the nation, a review of relevant papers, as well as annual reports are the data that will be analyzed to obtain this overview (Thread 1) and its data footprints (Thread 2) for Schistosomiasis.

Thread 1: (Chapter 3) The overview is the elimination backbone built by the stakeholders. Stakeholders are dedicated to contributing to the elimination and control of NTD, different stakeholders in the field has been racking their brains and leverage their professional expertise. Each stakeholder is assumed to best know their task and expertise, including the way they work, their relationship with other stakeholders, and the offerings they contribute to the world. In this phase, piece by piece, the puzzle of the overview will be collected from these stakeholders to frame the backbone of Schistosomiasis' controlling procedure.

Thread 2: (Chapter 4) Data is the product and catalyst of good intention. After the outline of the controlling situation is gradually revealed, the layer of "data" will be joining in the discussion based on thread 1. With this common goal, "to combat this epidemic promptly and effectively" alone, it is theoretically possible to link all the puzzle pieces of different stakeholders together via the data they' have created, as these links may demonstrate patterns of data footprints for mapping and analysis (Getoor, 2003).

Threads 1 and 2 will then be integrated for the discussion (Chapter 5). Together with the review of interviews previously done, the integrated overview of the data footprint will be tracked to discover usage patterns, latent information, and most important, the untapped digital data that posed gaps in the current Schistosomiasis elimination situation, aiming to advise future improvements.

The effectiveness of the research will be demonstrated by providing future development directions to SODOS. Future recommendations will be given at the end of the report to both the future research of untapped digital data and mHealth parties like SODOS.

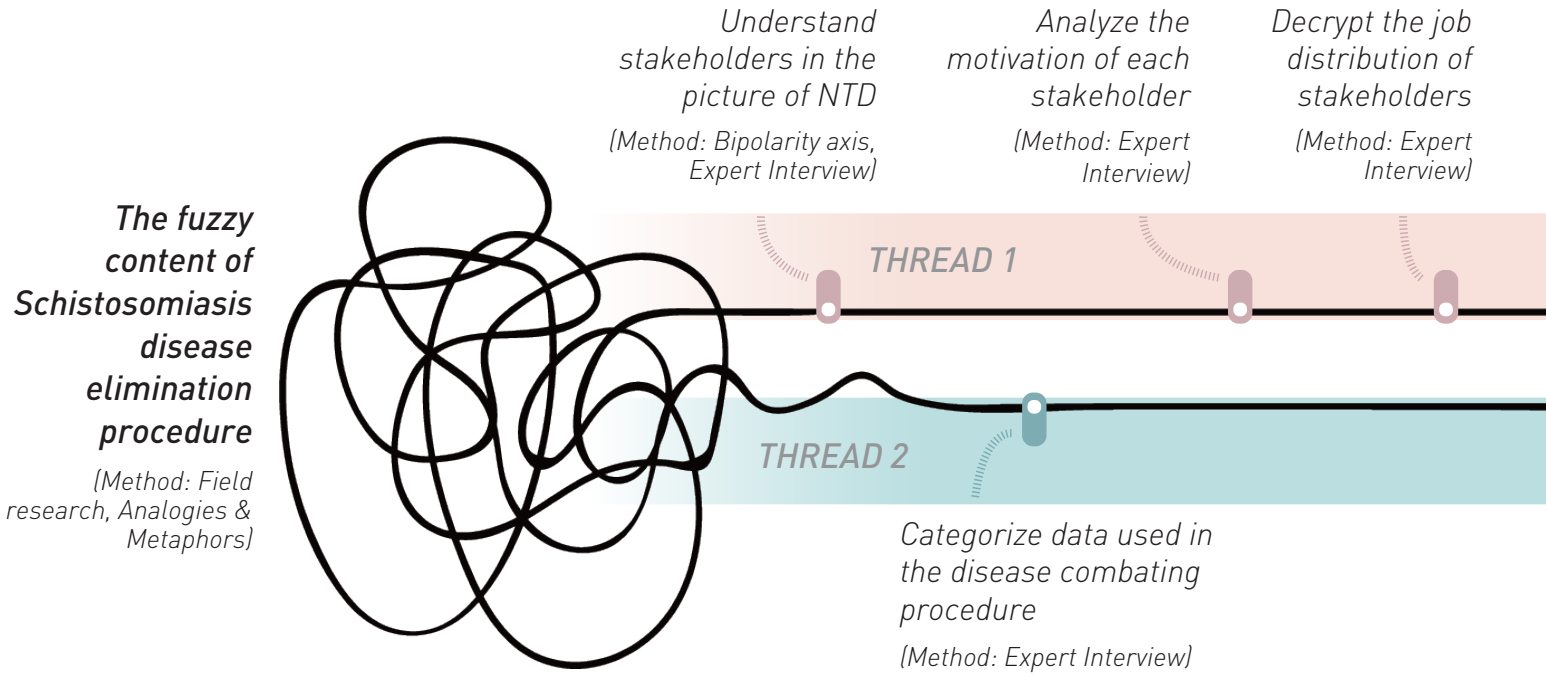
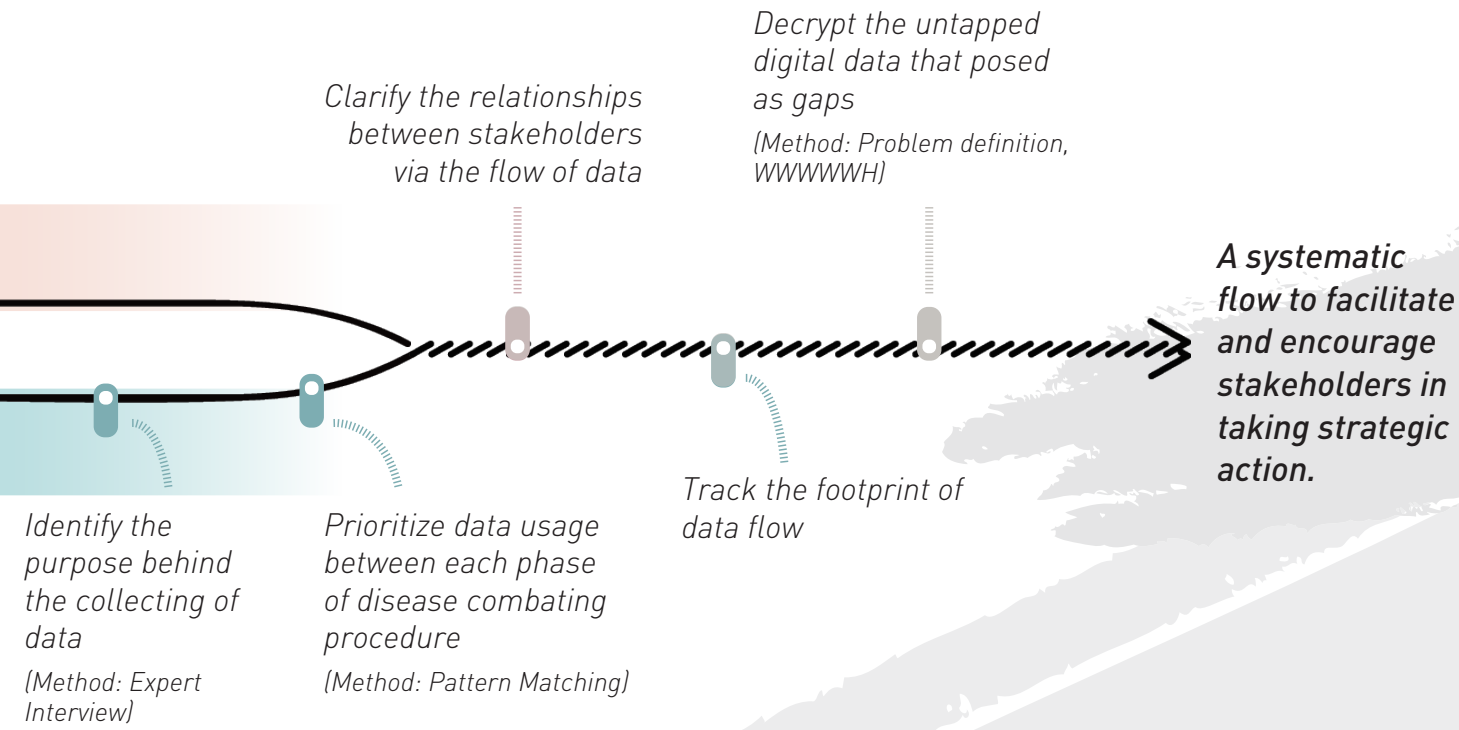

Understand stakeholders in the picture of NTD
(Method: Bipolarity axis, Expert Interview)
Analyze the motivation of each stakeholder
(Method: Expert Interview)
Decrypt the job distribution of stakeholders
(Method: Expert Interview)
The fuzzy content of Schistosomiasis disease elimination procedure
(Method: Field research, Analogies & Metaphors)
THREAD 1
THREAD 2
Categorize data used in the disease combating procedure
(Method: Expert Interview)

Figure 2-3: The approach to further explore the untapped digital data of Schistosomiasis. Thread 1 & 2 will each be discussed before concluding into an overview, aiming to provide insights for the direction of future developments.

The following graph marks the attempts of Schistosomiasis' data demystifying milestones: (allocated from left to right in accordance with the order of time)


Clarify the relationships between stakeholders via the flow of data
Decrypt the untapped digital data that posed as gaps
(Method: Problem definition, WWWWWH)
A systematic flow to facilitate and encourage stakeholders in taking strategic action.
Track the footprint of data flow
Identify the purpose behind the collecting of data
(Method: Expert Interview)
Prioritize data usage between each phase of disease combating procedure
(Method: Pattern Matching)

Each ~~stakeholder~~ runner has their experitise and characteristics.

Schisto. Relay Race
Runner List

Levels of different skills.

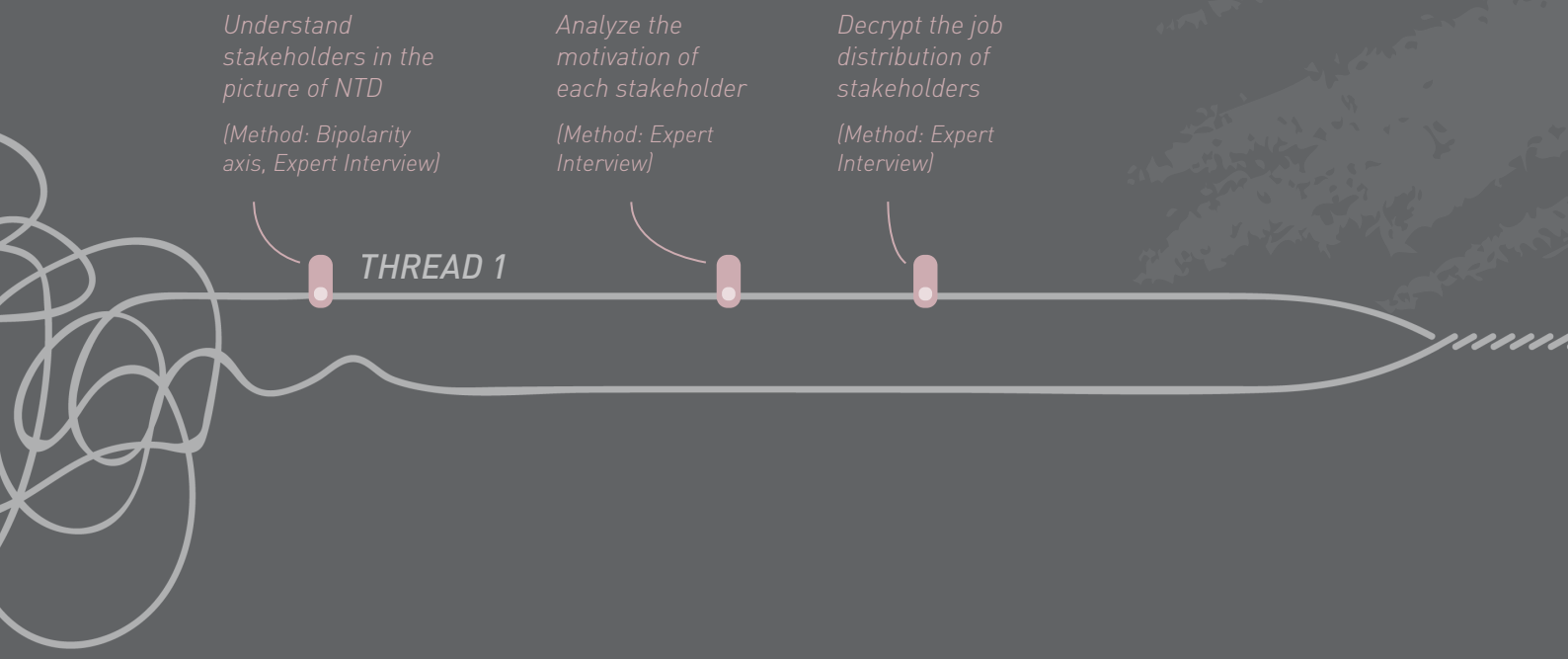
Specialized ~~scenario & content.~~ Landscape !

3 The elimination backstage - backbone built by the stakeholders

Health strategies, planning, and policies are more likely to get implemented effectively if all related stakeholders are involved in the development, discussion, and execution (WHO). Stakeholders of the disease controlling process may include government, non-profit or non-governmental organizations, community groups, political parties, UN agencies, the private sector, health care providers, and national parties when support or collaboration is needed.

As a disease that is likely to cause infection within its neighborhood, the relationship between players is fundamental to achieving elimination. In this chapter, the researcher will examine each stakeholder and the stakeholder's contribution to the whole picture of Schistosomiasis disease elimination, to puzzle out the overview.

In this chapter, different stakeholders will be briefly introduced, followed by the analysis between their interest, influence, position, and their offerings. Different goals of stakeholders will be compared via the bipolarity axis of mission and vision. Depending on the way they work, the task of these stakeholders will also be categorized into two: standardized and non-standardized cycle.


Understand stakeholders in the picture of NTD
(Method: Bipolarity axis, Expert Interview)
Analyze the motivation of each stakeholder
(Method: Expert Interview)
Decrypt the job distribution of stakeholders
(Method: Expert Interview)
THREAD 1

3.1 Players in the field

Each country designs and develops the structure of Schistosomiasis disease controlling procedure per a country's social structure, needs, and resources (White, 2015). Despite all the differences, common elements can be seen. Decision-makers at all levels have an obligation to identify different factors that have an influence and formulate appropriate strategies that will guide them towards their ultimate vision.

To explain the Schistosomiasis controlling situation, Kenya is used as an example in the research. The following graph listed the stakeholders involved in the controlling process by their level in the pyramid of healthcare (see figure 3-1).

Supranational Level
Global Organization (WHO) / Global Foundation (CIFF)
International Level
Agency (JICA) / University & International medical institutions
National Level
National Government / Local medical research institution (KEMRI) /
Local Non-governmental organizations
Province Level
Province Government / Local health facilities
Community Level
Community health workers & volunteers

Figure 3-1: Players involved in Kenya's Schistosomiasis controlling procedure

Supranational level

- Global Organization: WHO provided the needed drugs and disease control guidelines. Local WHO representative assists in the planning of survey testing and drug administration. With the advice from the different parties, WHO is able to provide meaningful results information as ultimate feedback to influence the field, and take the lead in improving the health situation of everyone.

- Global Foundation: CIFF (children investment fund foundation) is an independent philanthropic. They act as the biggest financial supporter in Kenya's Schistosomiasis controlling by fund support, providing personnel, and assist the arranging of venue, they help measure and evaluate the disease controlling progress.

International level

- Agency: Agencies such as JICA (Japan International Cooperation Agency), are a big influencer of Kenya's NTD controlling procedure. They might not be a member of the national controlling program, but can be coordinated for parasite control in the region. JICA assist pilot studies, field site training, and sustainable planning. (Uganda is supported by SCI - Schistosomiasis Control Initiative (charity); Zambia is supported by USAID - U.S. Agency for International Development)

- University: Universities with interest in the related field also takes part in shaping research findings into tangible impact. The London School of Hygiene & Tropical Medicine is an example of an international university that has a close connection with Kenya.

- International medical institutions: Based on the survey testing results, findings in the field and annual reports, meaningful aggregation, and analysis can be made. International medical research institutions look into the modeling for alternative elimination method, strategies, further provide advice to the field.

National level

- National Government: The National School-Based Deworming Programme (NSBDP) launched by the Kenya government, with the ministry of education and the ministry of health acting as the chair lead, made the Schistosomiasis elimination program a national level project. The Kenya government poses as the window to international and supranational resources, including receiving drugs from WHO, and annual report conducting.

- Local medical research institution: The local medical research institution at Kenya, KEMRI, plays the core role in carrying out health policies in Kenya. They are are part of the NSBDP. KEMRI conducts baseline survey testing for the monitoring and evaluation of neglected diseases. On a national level, they are also responsible for seeking cooperation with international institutes such as JICA to further develop sustainable future plannings for prevalent diseases like Schistosomiasis.

- Local Non-governmental organizations (NGO): There are plenty of NGOs actively assisting low-resource setting countries in fighting diseases. In terms of NGOs in Kenya, organizations like Evidence Action, Innovations for Poverty Action, Children's Investment Fund Foundation, and the END Fund, are all supportive backbones for disease controlling programs. For example, Take Evidence Action has the "Deworm the World Initiative" flagship program which takes part in the yearly MDA procedure. They are responsible for scheduling the program and assist Kenyans in building operational models for facing diseases.

Province level

- Province Government: Province government plays a joint leadership role in the implementing of MDA and prevalence survey testing. They are responsible for every primary school within the epidemic areas. Personnel from the provincial government act as a key role in the training of teachers, the distribution of drugs, and ensuring the safety of staff going deep into local fields.

- Local health facilities: Being a neglected disease, people with Schistosomiasis rarely seek help unless they are bothered by the symptoms, which also means they are in the chronic stage of the disease. In the case of Schistosomiasis, health facilities act in a support role in the diagnosing of samples. Labs are the primary health facilities (level 2 and 3) used to process samples (microscopic egg count). Technicians and medical staff with the required knowledge from these health facilities will be the main crew during the stage of diagnostic.

- Community health workers/ volunteers: Together with the province government, community health workers and volunteers are responsible for the community sensitization activities. These decentralized supporters are essential in strengthening citizen trust, utilization of health infrastructure, and reflecting the voice of the people.

Community level

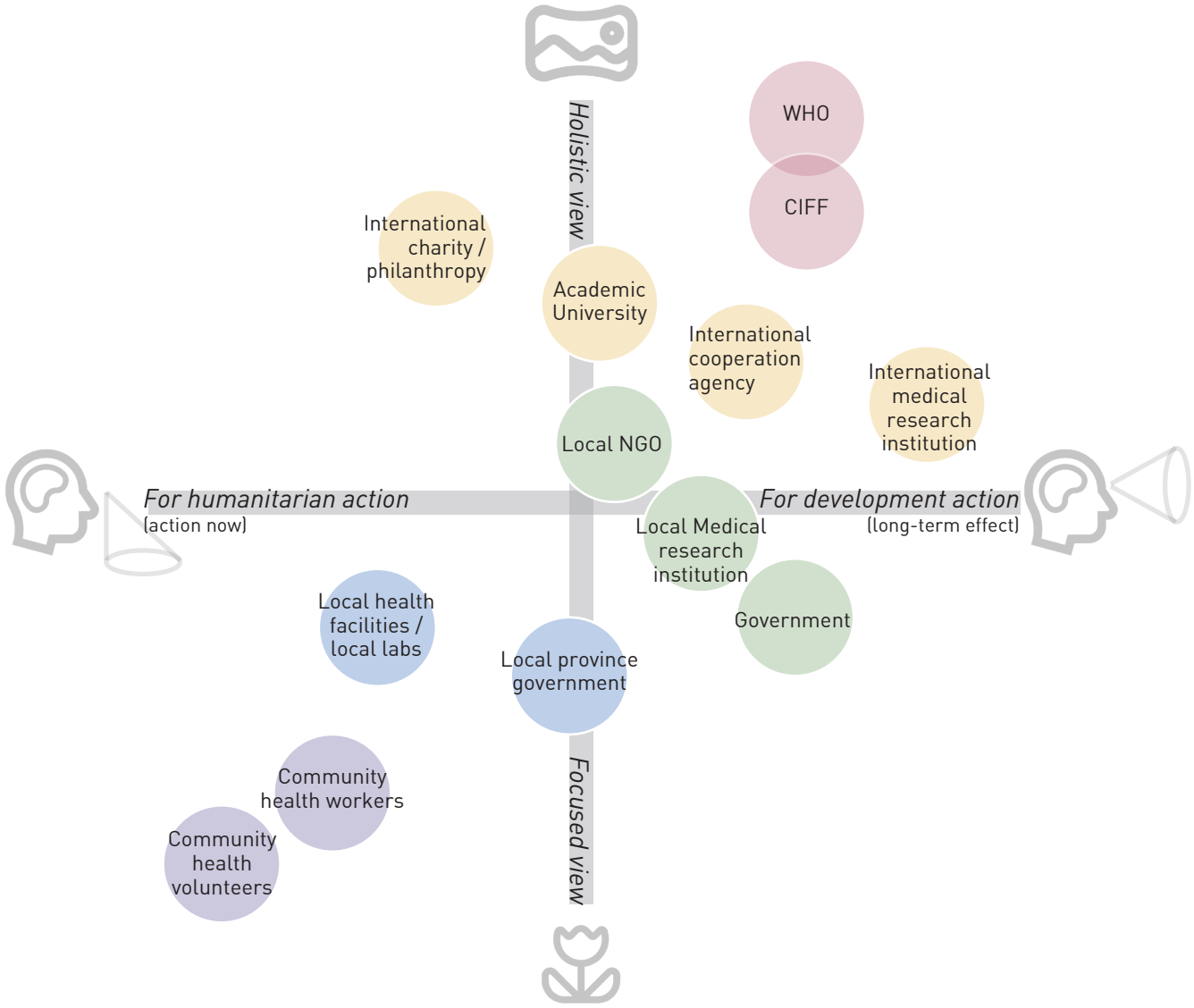


Figure 3-2: Bipolarity axis of stakeholder's mission and mission. The X-axis indicates a stakeholder's mission; Y-axis indicates a stakeholders' vision.

3.2 Mission and vision

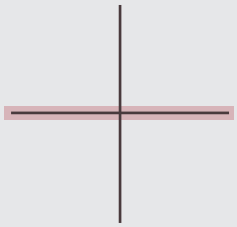
With different intentions, each stakeholder plays a different role. Despite the complexity of attainment and the diversity of task, with clearly defined goals and measurements, it is possible to compare the performance of these different stakeholders with each other (see Figure 3-2).

A clearly defined goal helps in setting priorities in creating objectives and is important in assuring everyone is heading towards the same destination. The mission

and vision statements are two of the most common tools to define goals, as they can act as the medium of conveying values and emphasizing the uniqueness of the organization (Leuthesser, 1997).

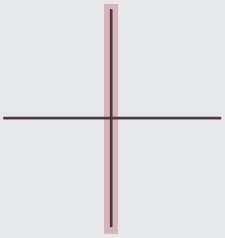
Both mission and vision statements define the purpose, but they are slightly different in defining the goal: the vision statement reflects how an organization would like to become in the future, while the mission statements describe the current state and primary objective (Vanderelst, 2017).

The X-axis indicates a stakeholder's mission: what kind of action is taken to heads towards a goal; the Y-axis indicates a stakeholders' vision: what do they ultimately want to seek and achieve in the long-run.



- **The polar of the X-axis for mission: Humanitarian action and development activities.**

Humanitarian action is focusing on short term relief until a long-term solution arrives. It is focusing on solving immediate needs and is often reactive, development actions, rather than short term response, it is focusing more on long term impacts. Targeting is usually the root cause of a problem; development actions are more proactive. The results may also come slower in pace.



- **The polar of the Y-axis for vision: Focused view and holistic view.**

The stakeholder that has holistic vision takes into consideration multiple relationships and elements in the complex system. Instead of static snapshots, they prefer to see the patterns of change and the interrelationship between phenomenon. In comparison with the holistic view, the focused view has a simpler objective and often aim to know the situation in a down to earth manner. The focused view is the foundation to have a holistic view, while the holistic view may have a bigger impact than a focused view.

The purpose of stakeholders explains their motive and intention in acting in the field of Schistosomiasis disease controlling. Understanding the vision and mission of other stakeholders also helps explore collaboration opportunities, and can be important for a party to reposition themselves.

Through the bipolarity axis for goal defining, patterns between mission and vision can be seen. Stakeholders with a more focused view in vision are more likely to act for humanitarian purposes, while stakeholders with a holistic vision work more for long-term effects via development actions. Coincidently, this phenomenon matches the pyramid of health care, as the lower level of healthcare mostly contributes to the humanitarian action, and stakeholders higher up the pyramid take a more holistic view when illustrating the future world. All stakeholders are of importance in keeping the system running. The following steps aim to more precisely articulate how these different stakeholders work together towards a disease-free world.

3.3 Role and task

The researcher takes Kenya's Schistosomiasis controlling situation as an example in explaining the role and task of these stakeholders, the illustration (Figure 3-3) on the next page displays how each stakeholder plays its role and works together in this controlling process.

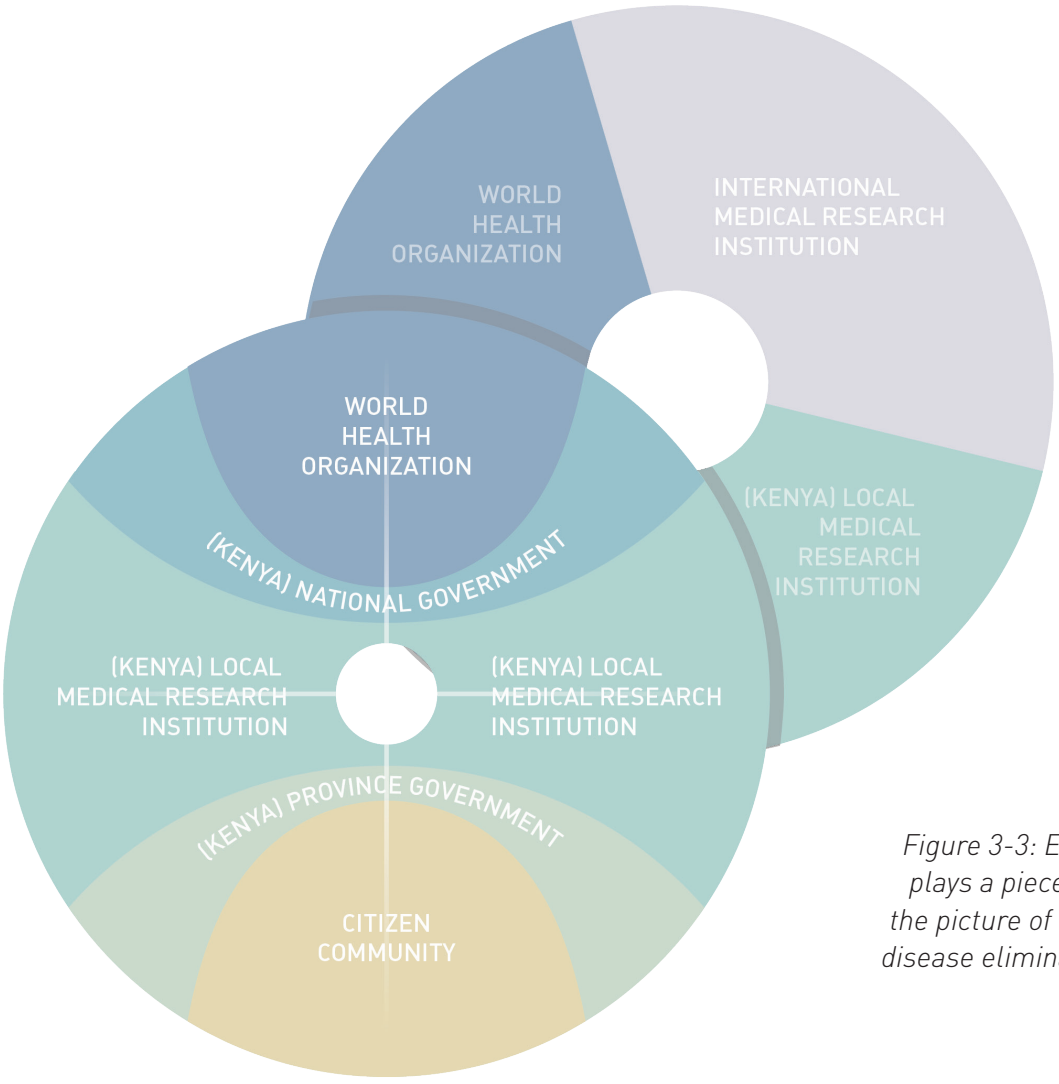


Figure 3-3: Each stakeholder plays a piece of the puzzle in the picture of Schistosomiasis disease elimination procedure.

Figure 3-4: Illustration of how people all over the world devote their effort in this picture of Schistosomiasis disease elimination procedure.

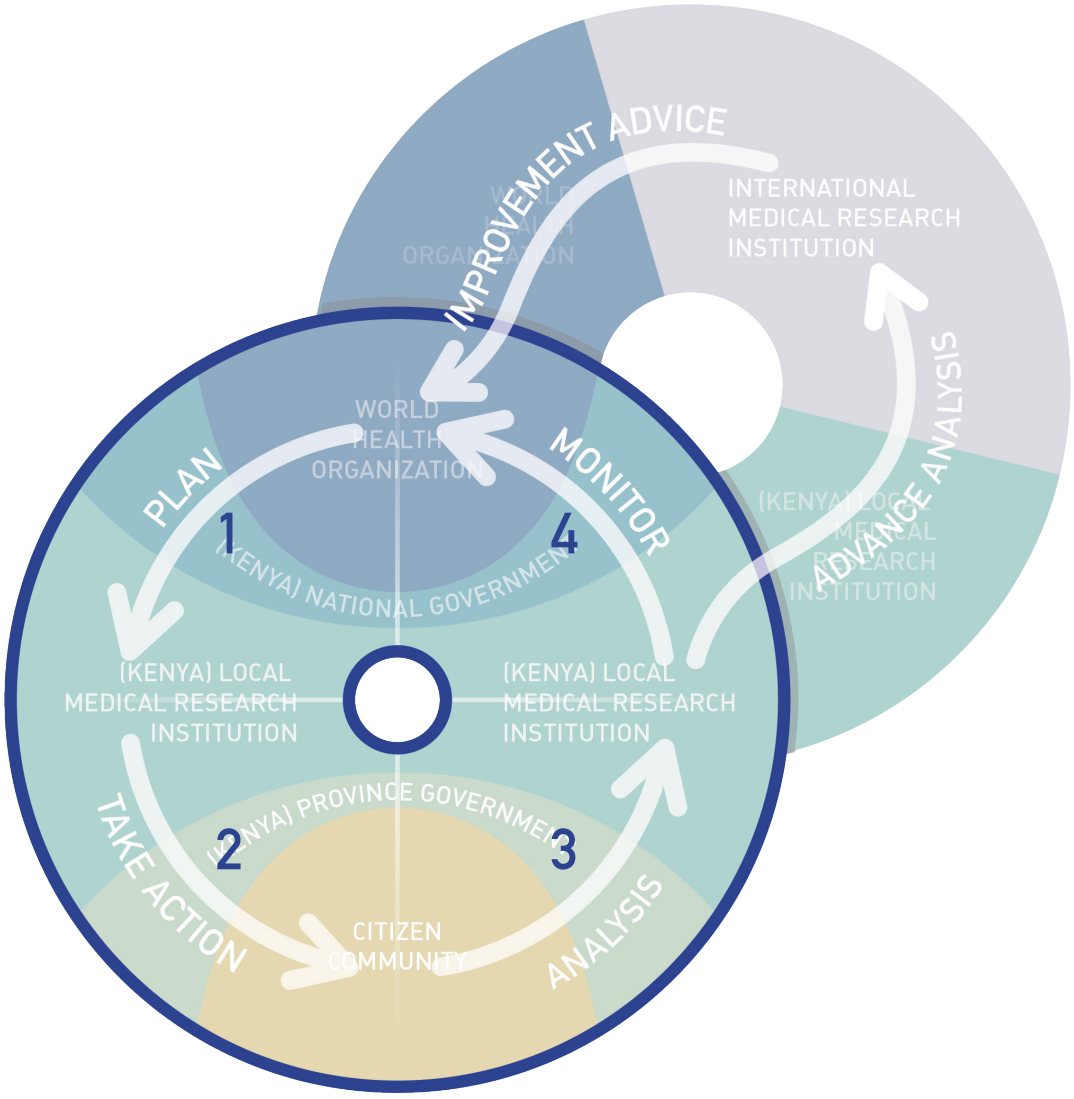
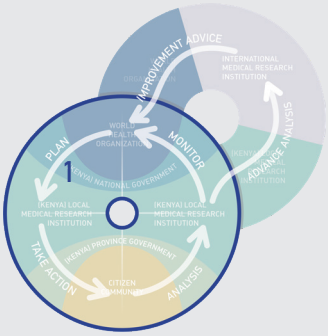


Figure 3-5: Where Standard flow happens (blue circle)

3.3.1 The left circle: Standard flow -- all about time, schedule, and responsibilities

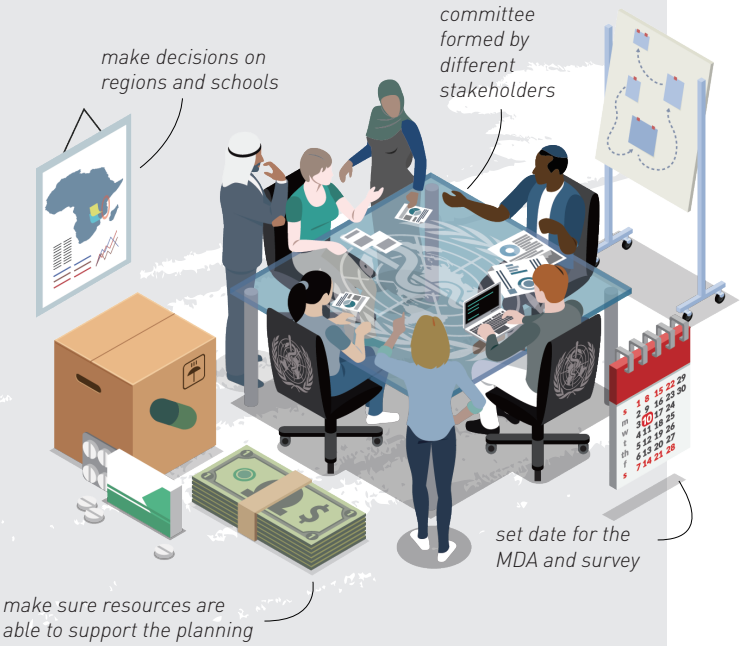
Stakeholders in the standard flow (Figure 3-5) tend to have a distinct division of powers and functions. Starting from the routine planning of MDA, a schedule can be completely expected in this cycle. Based on the guidelines provided by the WHO, each government customizes its MDA based on their country's situation to ensure efficiency. Division of responsibilities between stakeholders can be established.

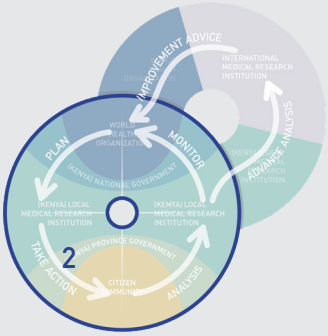


Planning

Starting from "planning" on the upper left corner, WHO together with KEMRI and Kenya national government forms the 'steering committee' and conduct planning to implement the WHO NTD guidelines.

With support from the WHO and other international parties, the Government of Kenya launched the National School-Based Deworming Programme in 2009. With the necessity of drug administration on a regular basis, the action of planning needs to have a routine flow. Lead by the government, the steering committee is formulated with people from KEMRI, WHO representatives, and local NGOs. Schedule planning will be done, the number of resources will be estimated, and necessary contacts will also be reached out before moving to the next phase. This regular planning action may be adjusted as needed as the need arises for educational research projects for testing innovative new methods or approaches.

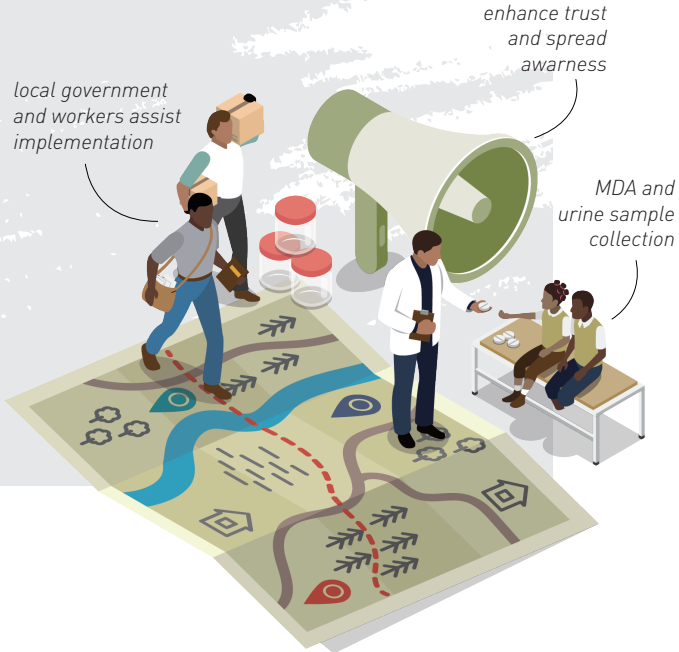

committee formed by different stakeholders
make decisions on regions and schools
set date for the MDA and survey
make sure resources are able to support the planning

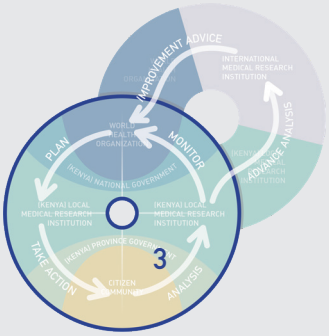


Take Action

The province government and community workers join KEMRI in undertaking the MDA as well as survey sample testing during the whole MDA procedure. The province government ensures the security and the community worker help sensitize the citizens before and during the MDA.

In the next stage of planning, the phase of practical action happens periodically. Personnel from the county and sub-county level join in to ensure the program is implemented in the targeted school. Teachers and citizens are sensitized with knowledge in action-taking assistance. Having a high degree of cooperation with the local government and community workers can substantially influence the procedure of MDA, as they play a routine role in distributing deworming drugs to school-aged children, managing sensitization activities in the community, and monitoring deworming procedure.

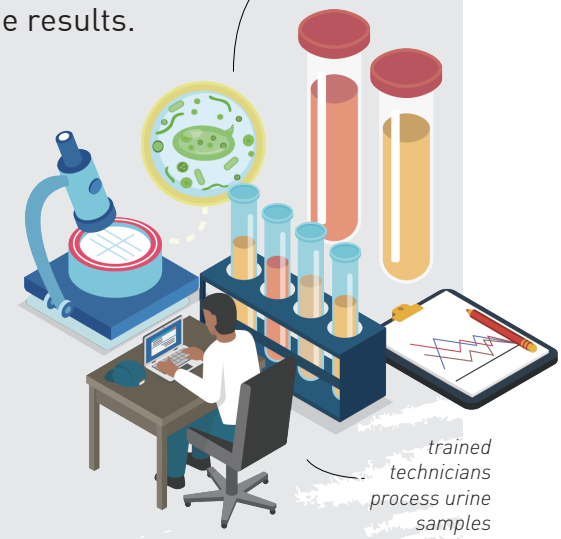

enhance trust and spread awarness
local government and workers assist implementation
MDA and urine sample collection



Analysis

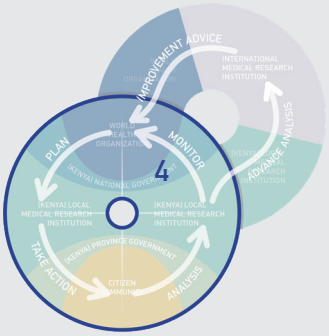
Urine samples are processed and examine at local labs from the health facilities. Technicians help process the samples and document the results.

Samples collected from school-aged children will be rushed to the local laboratory of a hospital at level 2 or 3 after field collecting. Trained technicians and laboratory experts will be examining the samples under the microscope for egg counting. The whole examining process can take up to 10 days. According to the latest Kenya MDA planning, a certain number of schools will be randomly selected for survey testing of disease prevalence before and after every MDA. Depending on the budget and the project, the survey testing may happen every year or every other year for better monitoring results.



identify Schistosoma eggs via microscope

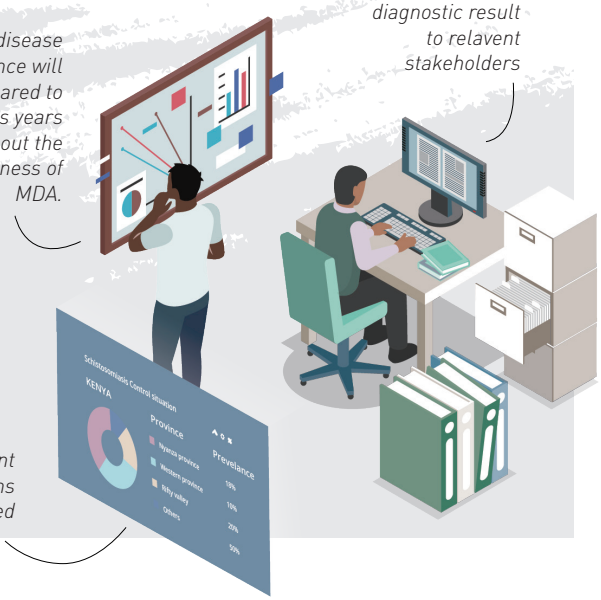
trained technicians process urine samples



Monitor

The information collected in the previous analysis step forms the disease prevalence. The results are documented, and the funder is notified of the results. The yearly result will be saved and compared to examine the effectiveness of the controlling program. Multiple partners may have contributed their effort to the deworming. To show that the provided resources are properly implemented, reporting will happen at this stage.

The prevalence and intensity of infection data are two of the most typical types of information collected from the result, as they can act as fundamental indicators in showing the impact of drug interventions (Toor & Turner, 2018). The numbers of these two indicators will be put together on a timeline to find out patterns, and monitor the changes according to demographic information such as gender, age, area of infections, etc., to understand the effectiveness of the drug and adjust approach if necessary.



disease prevalence will be compared to previous years to find out the effectiveness of MDA.

reporting the diagnostic result to relavent stakeholders

data from different schools and regions will be gathered

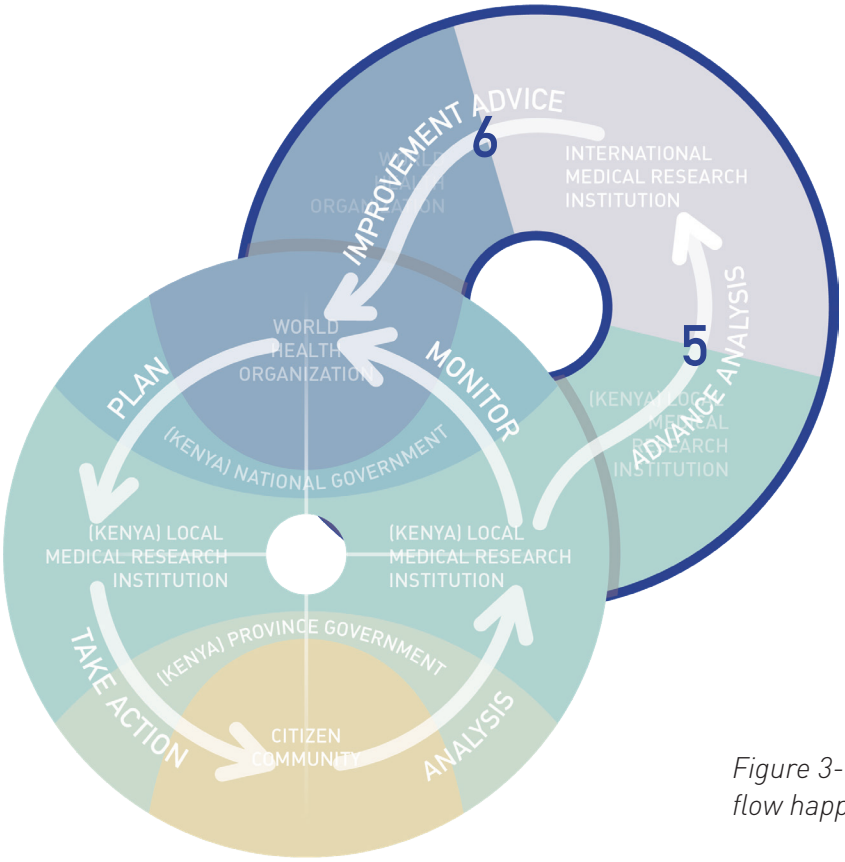
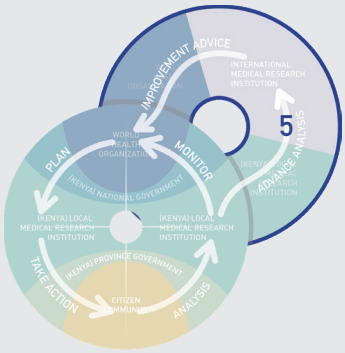


Figure 3-6: Where non-standard flow happens (blue circle)

3.3.2 The right circle: Non-standard flow -- all about discovering and predicting

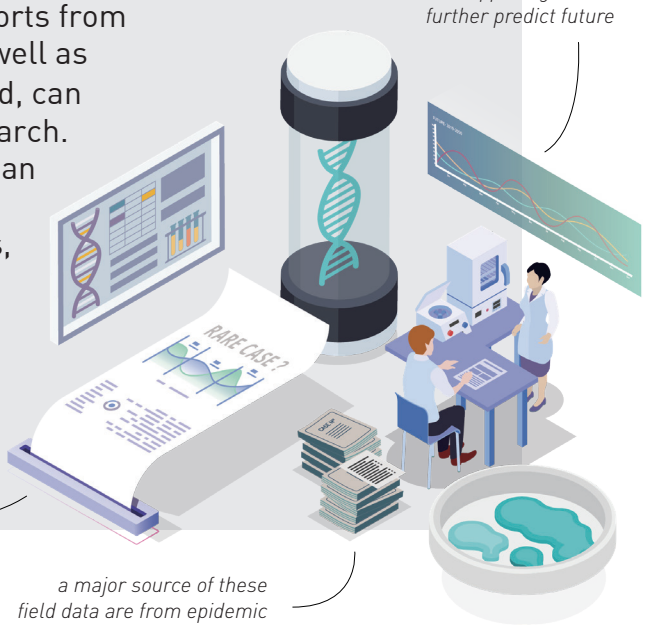
In comparison to a hierarchical relationship, mutual experience, exchanging, and influencing is more common in a non-standard flow (Figure 3-6). Action may happen irregularly without a fixed schedule, depending on the purpose of the project.



Advance analysis

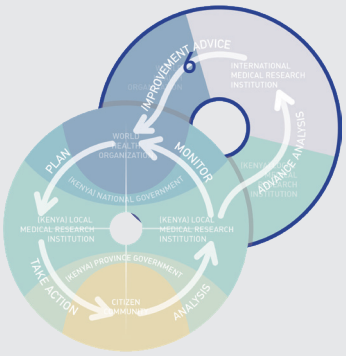
Parties like international research institutions, agencies, and foundations process advanced analysis to assist in future planning or strategy adjustment. Annual reports from epidemic countries, as well as related papers published, can be sources for this research. The advanced analysis can cover information from modeling for predictions, vaccination, and antigen development, to human behavior study.

understand what is happening now to further predict future



stakeholders outside the field will further look into data from the field

a major source of these field data are from epidemic countries' annual report



Advice for improvements

The published results from the advanced analysis will turn into input for global organizations like WHO to develop guidelines and adjust roadmaps for the future. The parties outside the local field will be invited to assist global conference and seminars, which have a high possibility to influence future planning to reach the goal of a better world.

conference and seminars held to gather insights globally

based on scientific research and modelings, researchers give advice to the eleminition approach.

3.4 Conclusion

Despite the common goal of detecting, preventing, and controlling the epidemic of Schistosomiasis, all players are given responsibilities and commitments at different levels. Thus everyone can play a complementary role.

As mentioned previously, Schistosomiasis is a disease that is likely to cause regional infection. The controlling of such a disease requires joint endeavors from medical and hygiene to education and infrastructure. It can be hard for stakeholders to stay out the issue when talking about helping rid the area of Schistosomiasis.

Having such an overview of stakeholder, on the one hand, helps those who are not in their position to have a closer feeling of other's key performance indicators and, on the other hand, encourages each stakeholder to realize how important he or she can be in his or her current position.

Based on the working flow of the current Schistosomiasis disease controlling the situation discussed in this chapter, in the next chapter, the researcher takes a deeper look deeper into the practical information that helps complement and supplement each other from a systematic way.

Relay batons ~~Data~~ are transferred along the way through ~~stakeholder's task completing~~ the journey of each runner :)

Each ~~stakeholder~~ runner does their best to complete the responsible ~~Task.~~ journey

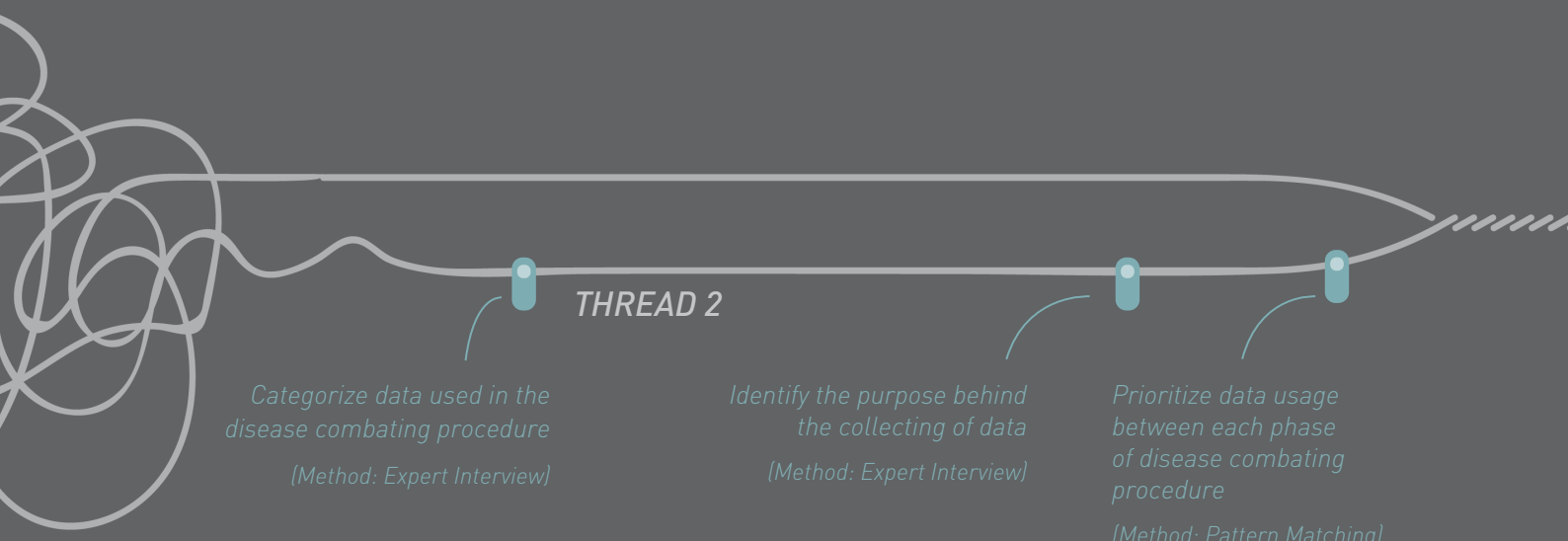
Relay batons ~~Data~~ are pass on ...

4 Data -
the product and catalyst of good intention

As seen in the previous chapter, the success of Schistosomiasis is related to the solidarity of stakeholders. The expertise and focus of each party increase the value of experience and knowledge exchange, which is of vital importance in supporting the activity happening in each phase.

Data act as important catalysts and evidence in treatment recommendations and policies (WHO, 2015). The orchestrating of the data can act as a significant additional resource to help stakeholders in the picture in creating a multiplying effect on the effort they have made when seeking new opportunities for improving disease elimination strategies.

Based on the available evidence, including the analysis in the previous chapter and interview results gathered from the visits made to various stakeholders and conferences, the research will be analyzing the data that links all the stakeholders together.


THREAD 2
Categorize data used in the disease combating procedure
(Method: Expert Interview)
Identify the purpose behind the collecting of data
(Method: Expert Interview)
Prioritize data usage between each phase of disease combating procedure
(Method: Pattern Matching)

4.1 Categories of data

For the analysis the expert interview results from the following stakeholders are consolidated:

- Community workers:
Country Coordinator & Communication Advisor from Healthy Entrepreneurs

- NGO:
Design Lead from MSF (Doctors without borders)

- Local Medical research institution:
Chief Research Officer and Assistant Director of Partnership and Collaboration from KEMRI (Kenya Medical Research Institute)

- International medical research institution:
Research Scientist at EMC (Erasmus Medical Center)

Interviewees were asked to briefly explain how they are related to the controlling of health maintenance or disease prevention, followed by what resources were needed to do their jobs, as well as what data is generated after they completed their tasks.

The following eight groups of data are principally synthesized and condensed by making reference to the study on "risk factors" that can influence the transmission ecology of Schistosomiasis and "remoting sensing data" for Schistosomiasis risk profiling. See Appendix B for the full assessed factors and data list of the previous research.

From the context analysis to the research of the parasite, the following eight groups of data is considered as the essential material (input) or result (output):
country-related data, infected area related data, citizen-related data, medical staff-related data, diagnostic result-related data, parasite-related data, resource-related data, and other abstract qualitative data.

The documentation of data can be influenced by the collection method, which is strongly related to the data collection strategy, complexity in the variable, the required accuracy, and the touchpoint of the collection (Rahman, 2015). Depending on the purpose and the characteristics of the information, the collection of data is also conducted at a

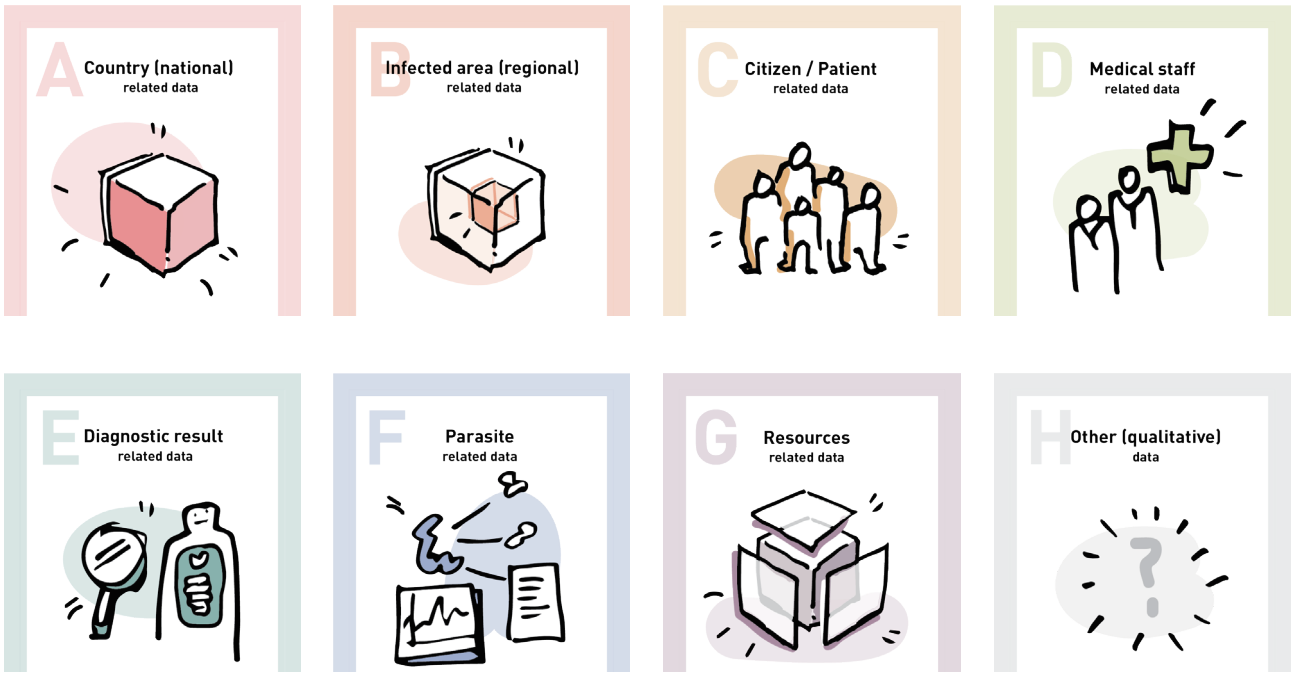


Figure 4-1: Tool cards are used to sensitize interviewee in recalling their working procedure. (see Appendix A)

sufficient interval frequency (will be further compared in chapter 5.2). For example, the disease prevalence should be constantly collected, while the population of the country can be collected and updated at a longer time interval. Compared to less frequently collected data, it will be ideal if frequently collected data can be documented automatically through sensor or generators instead of manually, as mechanically collecting data has a chance to minimize errors, and reduce cost. (Rahman, 2015) The current collecting method of these data is listed in table 4-2.

The eight groups of data are as following:

- Country related data: Population/Gender ratio/Migration rate/Literacy rate
- Infected area related data: Infected area location/Weather condition/Population
- Citizen related data: Age/Adherence
- Medical staff-related data: Number of medical staff/Workload of medical staff
- Diagnostic result related data: Date and time/Amount of urine/Appearance of urine
  Occult blood in urine/Parasite
- Parasite related data: Prevalence/Taxon/Host species/Intensity/Locality
- Resource-related data: Drug coverage/Budget/Equipment
- Other data: Frustration/Improvement advice

	Population of the country	Gender ratio of the country	Migration rate of the country	Literacy rate of the country	Infected area location	Weather condition of infected area	Population of infected area	Age of patient	Drug adherence of citizen	Number of medical staff	The workload of medical staff	Date and time of diagnostic	Amount of urine for diagnostic	Appearance of urine	Occult blood in the urine	Parasite
	Country related data				Infected area related data			Citizen related data		Medical staff related data		Diagnostic result related data				
Mostly captured (via digital channel)					V	V						V	V		V	
Mostly collected (via qualitative documentation)	V	V	V	V	V		V	V	V	V	V	V	V	V	V	V

	Parasite prevalence	Parasite taxon	Host species	Parasite intensity	Parasite locality	Drug coverage	Budget	Equipment	Frustration	Improvement advice
	Parasite related data					Resource-related data			Other data	
Mostly captured (via digital channel)	V									
Mostly collected (via qualitative documentation)	V	V	V	V	V	V	V	V	V	V

Table 4-2: The current collecting method of data that are relevant to Schistosomiasis disease controlling

4.2 Purpose of data collection

Data can be seen as symbols that reflect objects and events, while information can be seen as a series of reprocessed data. The direction of processing data is thus of vital importance in increasing its usefulness and value (Ackoff, 1989).

Through the interviews, the researcher found overlapping in the requesting of the data type. However, due to the difference in the role of stakeholders and the different stages that they each take actions, the same data may be used differently, at a different degree, or for a different purpose. For example: for the local government, diagnostic-result-related data has the value in reflecting the health situation of the citizen, however, for international research institutions, the value of diagnostic-result-related data may be mainly used to indicate the effectiveness of the newly developed diagnostic method.

Functional aspect makes data into useful information. Having a well-defined view of the main purpose for collecting data can help direct future innovation (Akvo). Based on the position and role of each interviewee (discussed in the previous chapter), it is possible to cross-reference and correlate the response in finding patterns of the reason for collecting the data. According to the composite results of the interviews, the main purpose of each data collection stages are as follows: (see figure 4-3)

1. Planning: allocate resources, assist decision making, plan schedule, distribute jobs, and clarify the goal.
2. Action taking: ensure a smooth operation, track progress, and be ready to redeploy funder exceptional circumstances.
3. Analyzing: conduct result and ensure accuracy.
4. Monitoring: check the effectiveness, monitor progress, report results, and further propose a direction for improvements.
5. Advance analyzing: provide sufficient variables for research liability.
6. Advising: adjust future steps based on experience, expert advice, and research predictions.

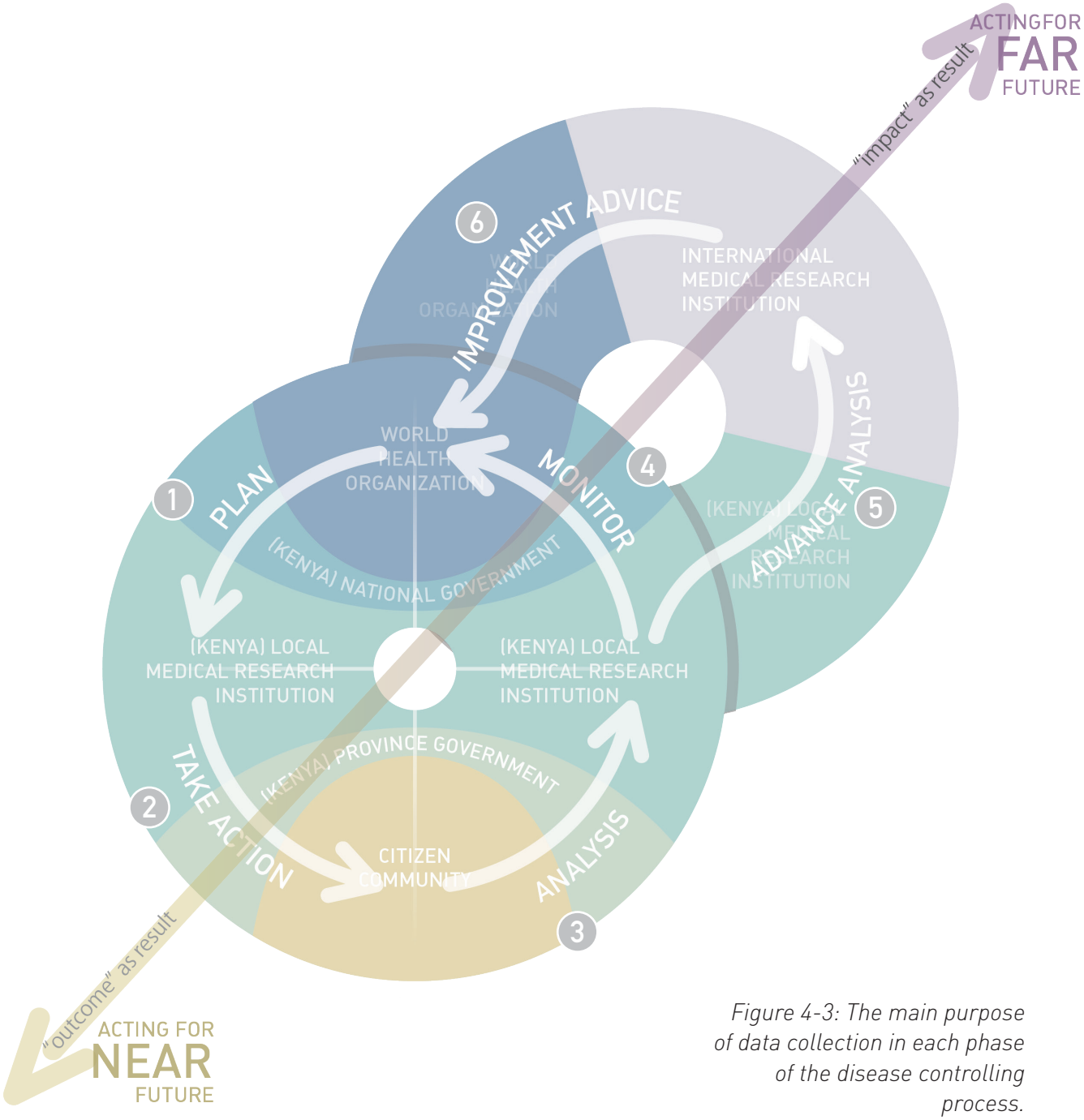


Figure 4-3: The main purpose of data collection in each phase of the disease controlling process.

As a whole, the purpose of data collection can be seen aiming for the near or far future. Taking action to eradicate worms in people's body can be seen as the one closest to the immediate basic needs. The results gathered from the field act as the foundation for advance analyzing, which prods for the root cause and aim to seek impact in further research. The process of advising and planning then implementation allows for future preparation and creates a possibility of ta disease-free ideal world. This phenomenon also is in line with the X-axis for stakeholder mission previously discussed in chapter 3.2.

4.3 Data in each step of the elimination process

Even though having the perfect quality and amount of data can increase the efficiency of working, having a comprehensive overview of what and when certain data is needed can increase the planning of a thoughtful and effective strategy on the long-term (Akvo).

Based on the working cycle previously discussed in chapter 3.3, these eight types of data are marked by their moment of usage and importance. This overview presented how the streams of data pass through all these different phases of disease control (see figure 4-4).

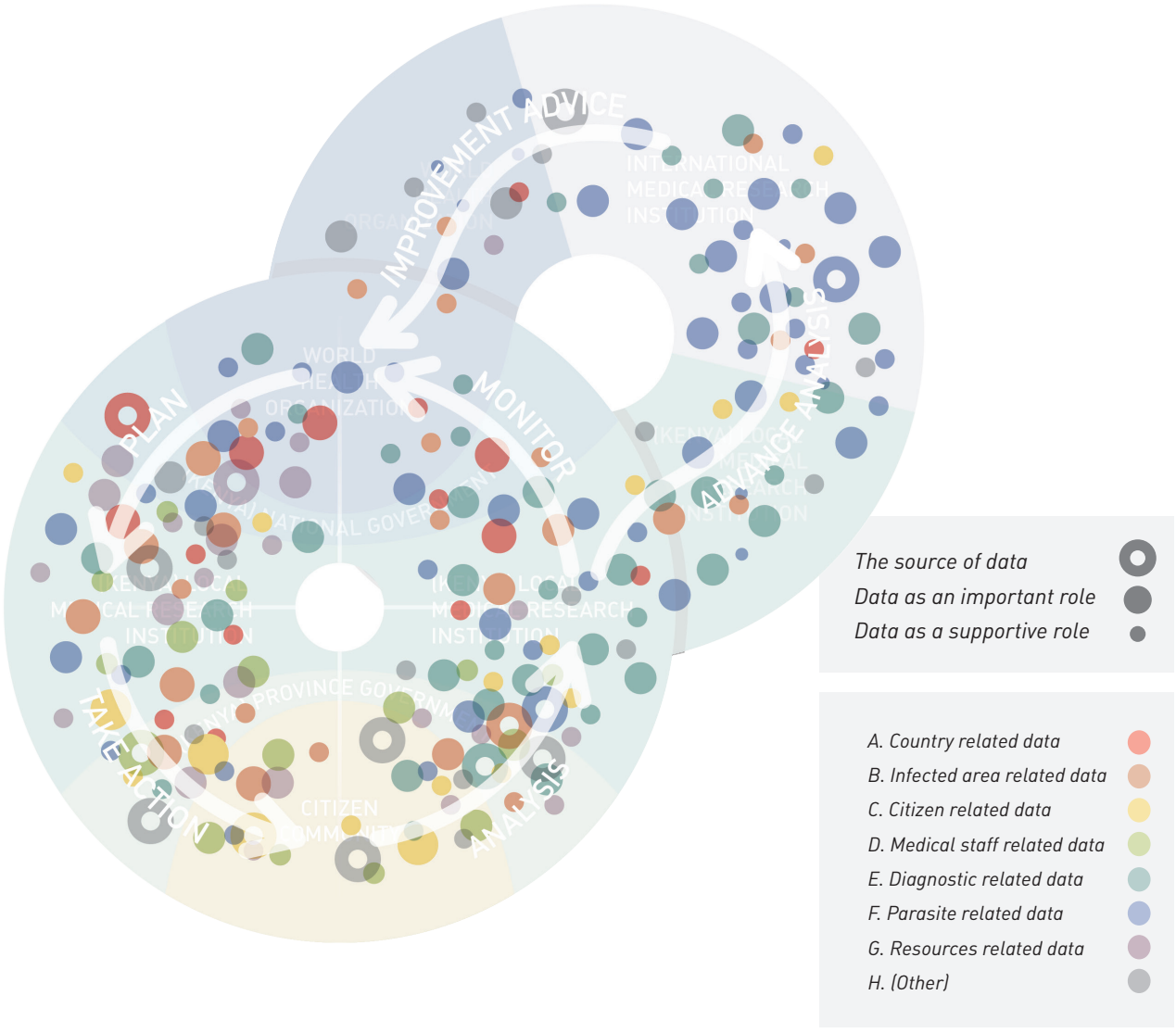
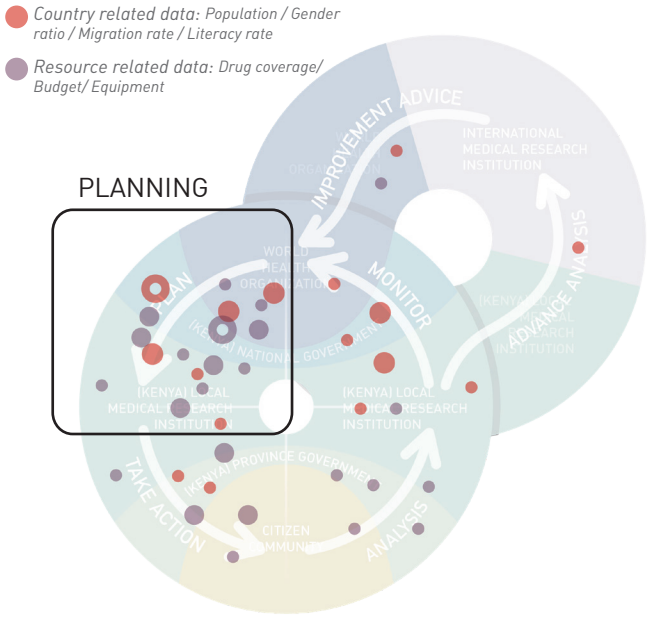


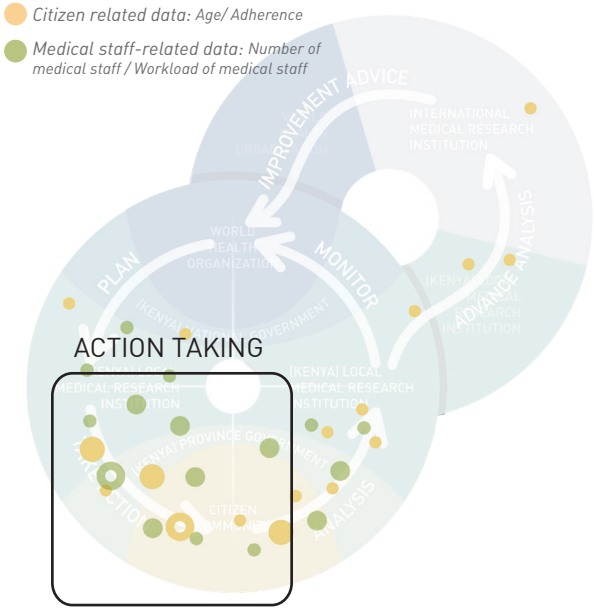
Figure 4-4: The overview of data usage and importance within the current Schistosomiasis controlling procedure.

Although data from the different aspect is still required to illustrate the complete picture at different phases, patterns can be seen from the documentation of data. The following assumptions can be deduced based on the patterns:

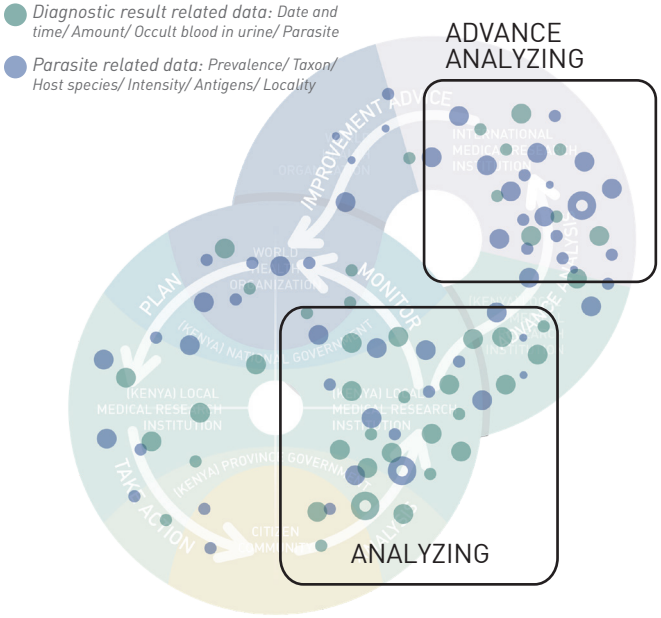
1. Country and resource-related data are most needed during the MDA planning phase.



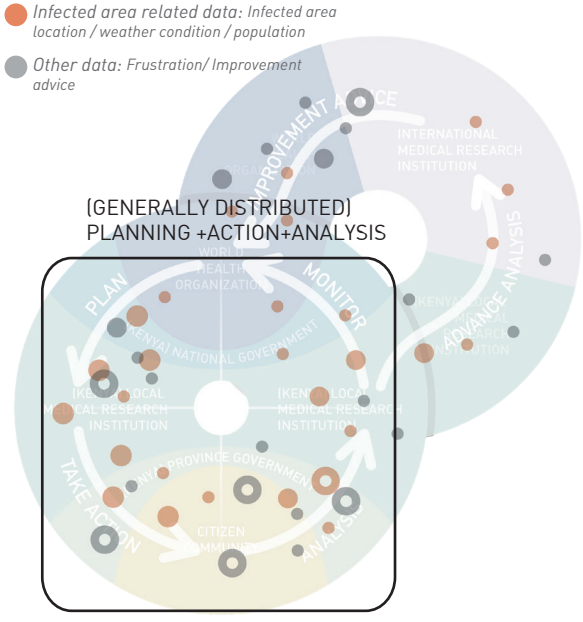
2. Citizen and medical staffs related data are most needed during the conducting of MDA and survey sample testing.



3. Diagnostic results and the information of the Schistosoma parasite is essential throughout the entire disease controlling process. These two types of information also play a key role in the stage of sample diagnostic and advanced analyses.


Diagnostic result related data: Date and time/ Amount/ Occult blood in urine/ Parasite
Parasite related data: Prevalence/ Taxon/ Host species/ Intensity/ Antigens/ Locality
ADVANCE ANALYZING
ANALYZING
IMPROVEMENT ADVICE
MONITOR
PLAN

4. IInformation on disease infected areas has a crucial role to play in the routine controlling cycle (left). Opinions and concerns regarding frustrations and advice can occur at all phases. Compared to the other six types of data; by comparison, these two are uniformly distributed.



4.4 Conclusion

Data can be multi-relational. A certain type of data can be considered as the output of one party but used as an input for the other one. After screening out the commonalities in data, and streamlining them in the current disease controlling procedure, the data footprints in this chapter can assist us in further understand the following two aspects:

- The main purpose of collecting a certain type of data.
- What data is most needed in supporting the activity.

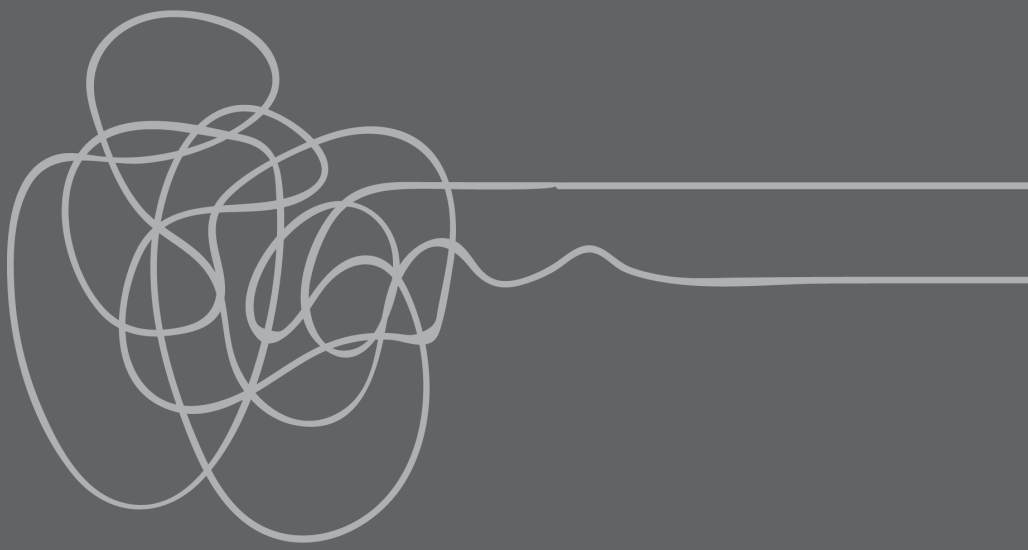
	Planning	Action taking	Analyzing	Monitoring	Advance analyzing	Advising
Country related data	HIGH	LOW	LOW	MEDIUM HIGH	LOW	MEDIUM LOW
Infected area related data	HIGH	HIGH	HIGH	MEDIUM HIGH	MEDIUM HIGH	MEDIUM HIGH
Citizen related data	LOW	HIGH	MEDIUM HIGH	MEDIUM LOW	MEDIUM LOW	LOW
Medical staff-related data	MEDIUM HIGH	HIGH	HIGH	LOW	LOW	LOW
Diagnostic result related data	MEDIUM LOW	LOW	HIGH	HIGH	HIGH	HIGH
Parasite related data	MEDIUM LOW	LOW	HIGH	MEDIUM HIGH	HIGH	MEDIUM HIGH
Resource-related data	HIGH	HIGH	MEDIUM HIGH	LOW	MEDIUM LOW	LOW
Other data	HIGH	MEDIUM LOW	MEDIUM LOW	LOW	LOW	HIGH

(HIGH= Direct influence / MEDIUM HIGH= Indirect influence / MEDIUM LOW= Don't always create influence / LOW= No influence)

Understanding the disease controlling situation is an indispensable phase before making an effective approach (WHO, 2013). The next chapter will further look into how mapping the footprint of these comparable indicators, data, and experience that are shared within the field of Schistosomiasis disease controlling can yield a light of opportunity for new data-driven approach in the future.

Having an overview of the ~~elimination procedure~~ relay race running track can help trigger strategic planning for the future !

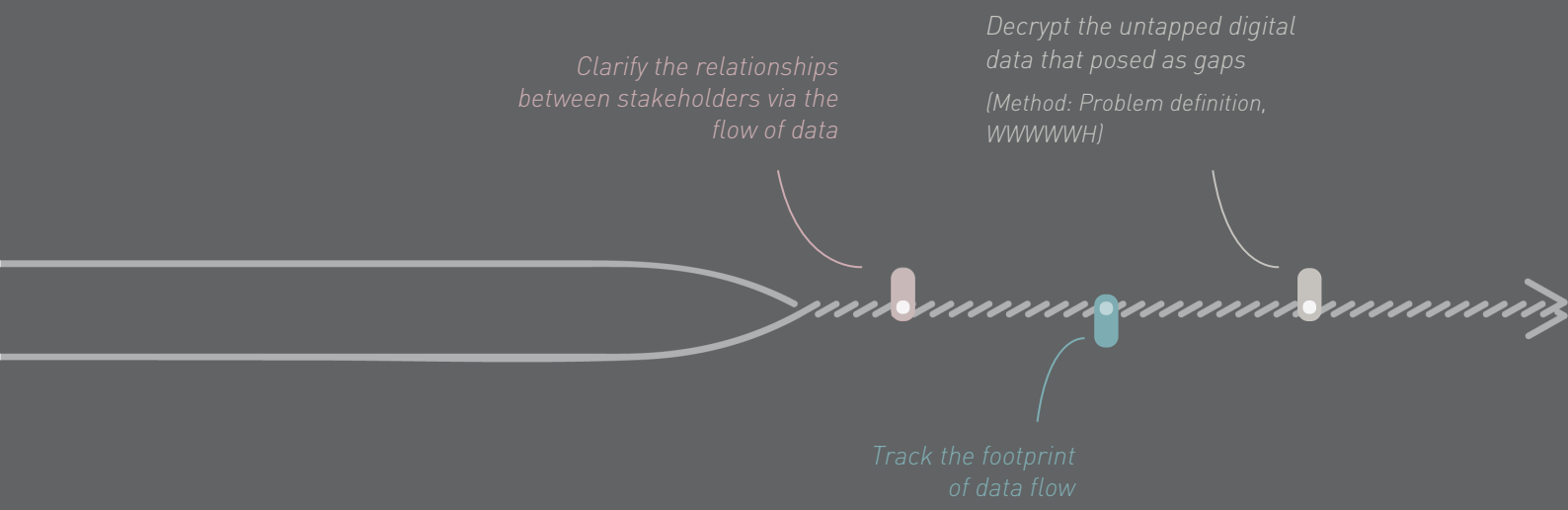
The approaching new era of digital technology...



5 Demystify digital data footprints
in Schistosomiasis disease controlling process

The operational relationship between all these different parties that assist the performance of the Schistosomiasis controlling process pose as the vital influence in building the entire system. Data, which can form into meaningful pieces of information, can be seen as the product that reflects performance in each stage; data can also act as a key catalyst in strengthening the scientific disease controlling approach. By combining these two aspects, the researcher will integrate the overall relationship between the stakeholders and the data that flow between these components.

Through the discussion of the map, the untapped digital data that reflect gaps in the current Schistosomiasis elimination situation will be presented at the end of this chapter, the aim is to exploit these rich sources of information to find further information regarding how the current approach can be improved. It is important to note that the map of data footprints presented in the chapter should be a work in progress. Regular updates and inputs will help keep the mapping of data flow up-to-date and thus complete.


Clarify the relationships between stakeholders via the flow of data
Decrypt the untapped digital data that posed as gaps
(Method: Problem definition, WWWWWH)
Track the footprint of data flow

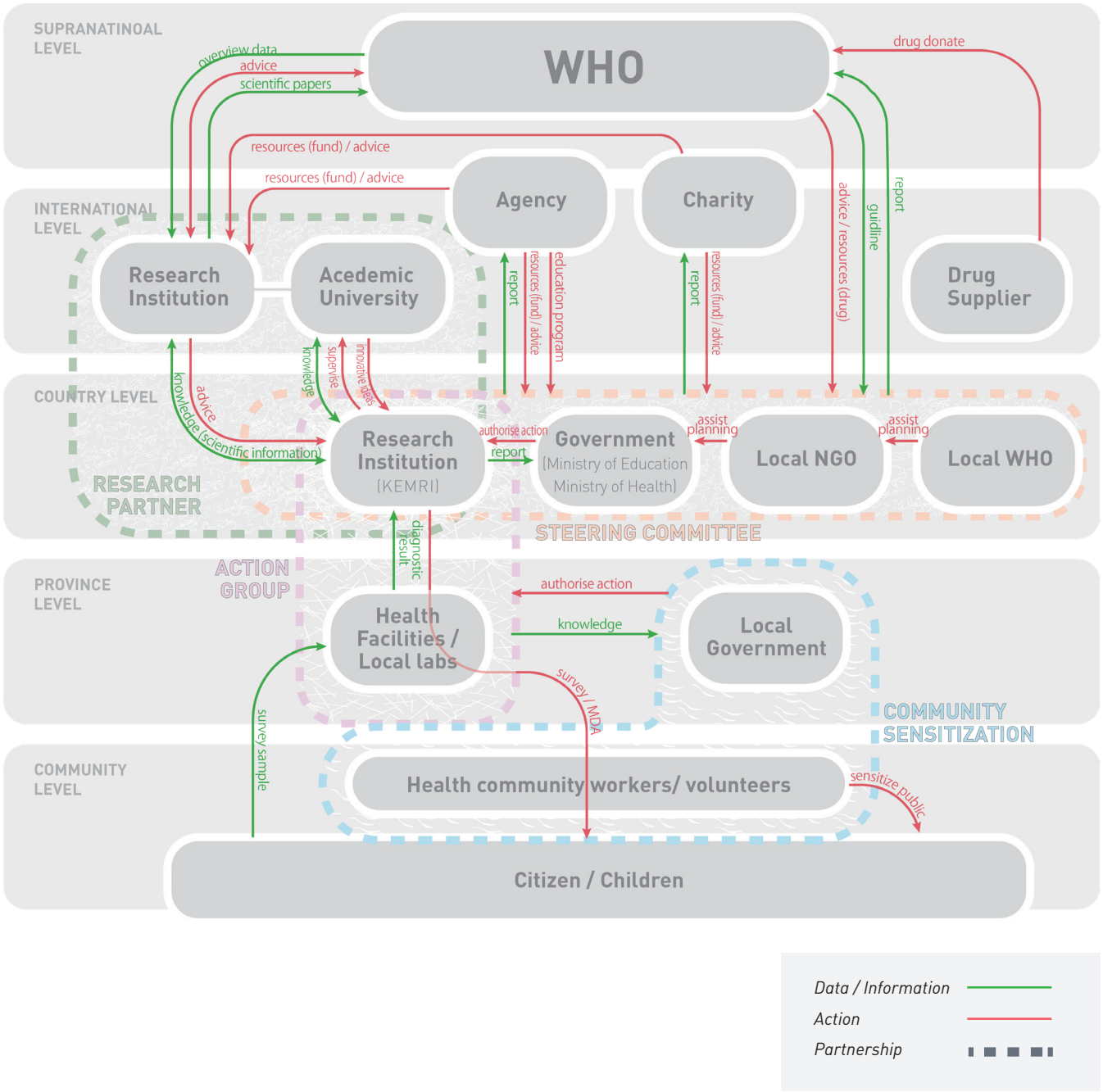


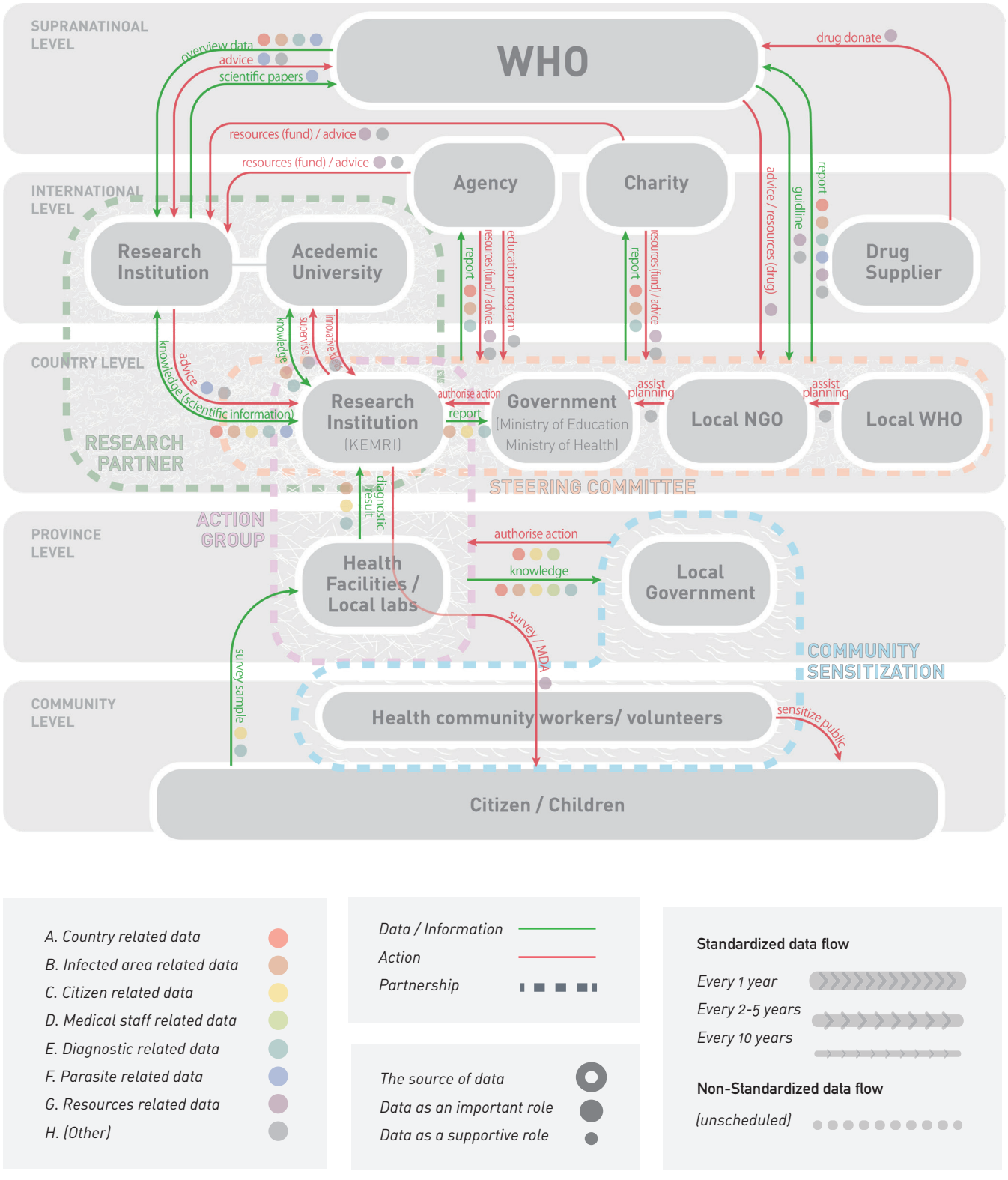
Figure 5-1: The relationship between stakeholders in this field of Schistosomiasis controlling situation (Based on the situation in Kenya in 2019)

5.1 Relationship between stakeholders

Together with the influential level of healthcare (from the community level to supranational level) (on the left column), the relation between each stakeholder is mapped. Again, despite the situation differently in different countries, the map is currently illustrated based on the Schistosomiasis controlling situation in Kenya (see Figure 5-1).

The dotted line grouped the parties that partner for certain action taking activities; the red lines indicated their behavior action; the green lines marked the direction of content transferred between them. With this brief view, loops and cycle can be seen. Urine survey samples that carry the health situation of the citizens in the epidemic areas can be seen as the beginning of the cycle.

Starting with the urine survey samples that carry the health situation of the citizen in the epidemic areas, are the original forms of a great deal of information, which is either translated to different kinds of input or motivate the collection of other data. Via stakeholders at the country level, data are then spread to all kinds of parties. Players on the international level are relatively diverse. They are all interested in the latest disease situation, but in response takes a different action. The directions of information flow can be thus seen generally going upward, and then back again from the supranational level to the country level before influencing the local field.

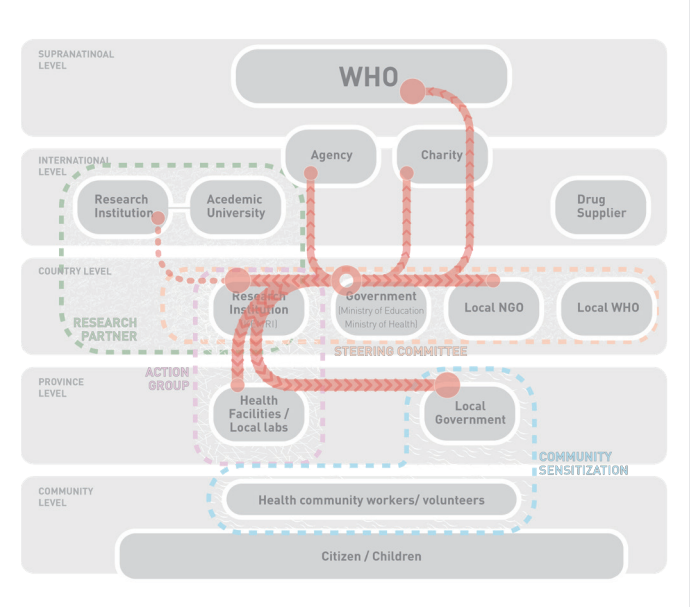


Figures 5-2: The flowing of data together with the relationship between stakeholders in this field of Schistosomiasis controlling situation (Based on the situation in Kenya in 2019)

5.2 The flowing of data and information

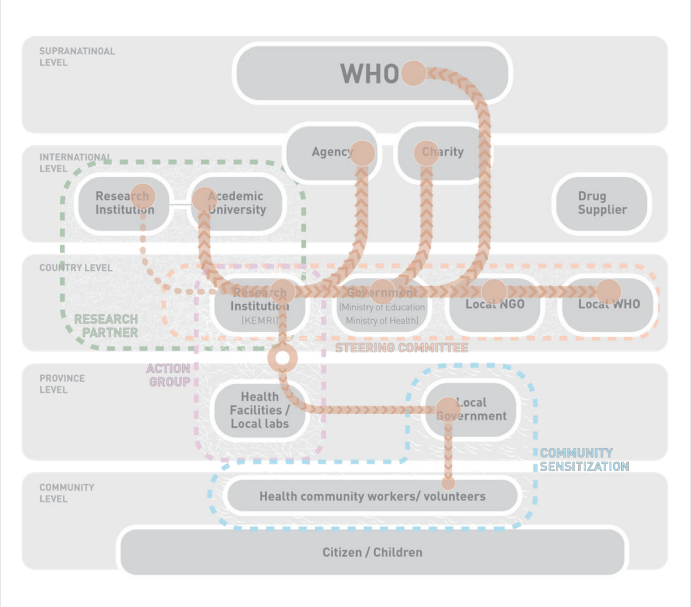
By matching the data flow with the relationship, the map is formulated (Figures 5-2). With a close examination of each of the data, the sets of graphs below illustrate each stream of data that flows through the disease controlling procedure. The interaction can be seen happening at a different frequency. From year information flow such as the annual drug administration, up to strategy roadmap planning that renews every ten years.

Dotted lines with the round edge represent the interaction that belongs to the non-standardized flow (see chapter 3.3.2), which happens accordingly without a fixed schedule based on the demand for certain projects or mission. The thickest line represents the data that are transferred at the highest frequency (yearly or within a year); the semi-thick line represents the data that transferred from two years up to five years; while the thinnest line represents the data that takes the longest to be updated. The green and red lines are edged with arrows to show the direction of such data. The nodes are spotted at stakeholders who make use of such data, with the size of the node showcasing the degree of importance.



A. Country-related data:

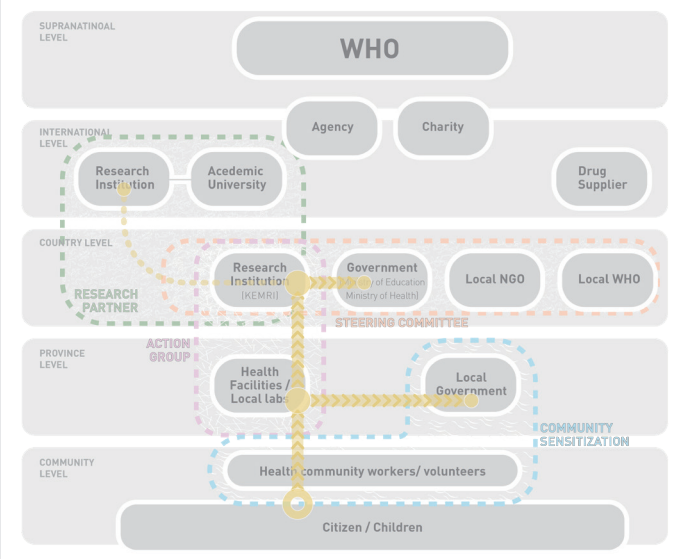
Country related data that can assist the controlling procedure includes population, gender ratio, migration rate, and literacy rate. These data are brought together and managed mostly by the government. Considered as part of the basic information of the context, they are often transferred together with the annual report with a more specific purpose or announced on the national database. Stakeholders that play an important guiding role in MDA or survey testing procedure are more likely to find country-related data essential for their task, while other stakeholders might not keep such a close view on this type of data, as the figure of country-related data takes a longer time to change.



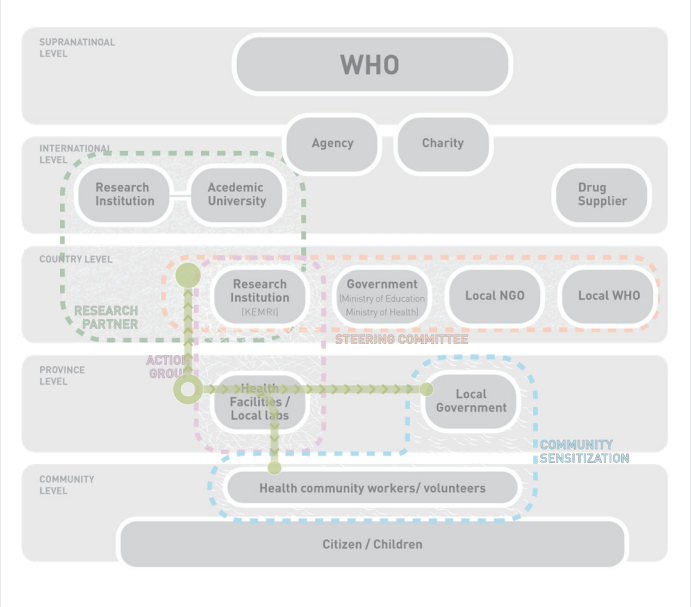
B. Infected area related data:

Infected-area-related data are derivatives of the disease prevalent survey testing. Data that are considered to be part of the group are location, weather conditions, and population. Compare to *country-related data* that are on a general level; *infected area-related-data* are relevant to stakeholders that have a more narrowly focused on the Schistosomiasis projects or program. MDA and survey results are the main channel of thedata, the frequency of infected area related data thus comes along with the scheduling of these field activities.

C. Citizen related-data:

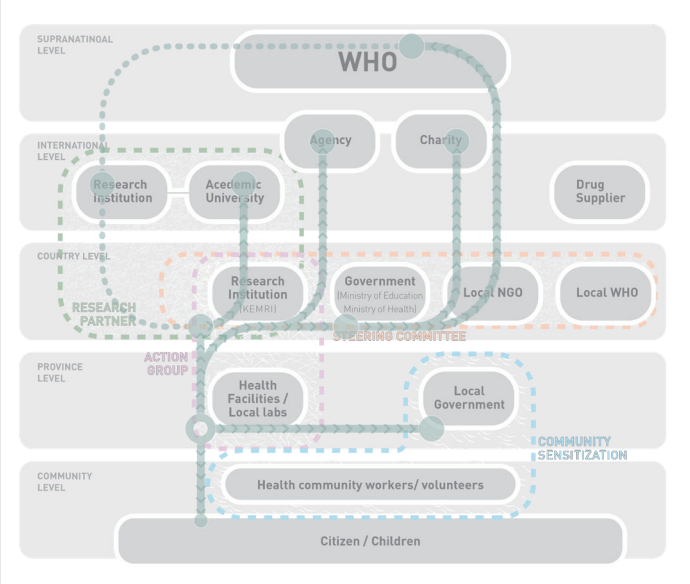


Relevant citizen-related data are age and the drug adherence of patients. As mentioned previously, school-age children generate the highest intensity of Schistosoma worm intensity among all age groups. Knowing the age range of the target group is essential for conducting MDA and survey testing. As mentioned in chapter 1.1.4, the adherence of synthetic anthelmintic drug, praziquantel, has recently been called into question when discussing the hurdles of disease elimination. However, these two data are currently beyond the list of reporting. Since they are close to the data source, stakeholders working towards the community level are more likely to have access in these non-officially-reported messages. It is noteworthy that stakeholders at the international level have begun to be concerned about citizen related data due to their interest in Schistosomiasis disease controlling on the individual level.



D. Medical staff-related data:

Medical staff-related data is useful for the planning of survey testing. Relying on manual operation of microscopic egg count, the number of medical staff, who are also related to the workload of medical staff, is of vital importance to the efficiency of the urine sample processing procedure.

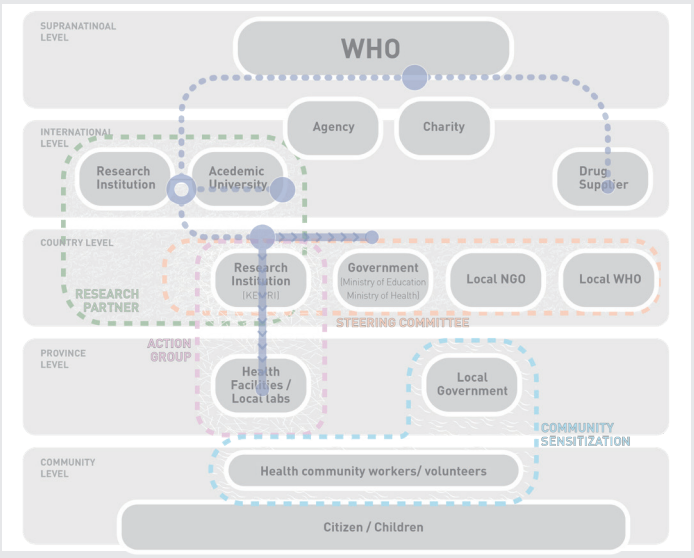


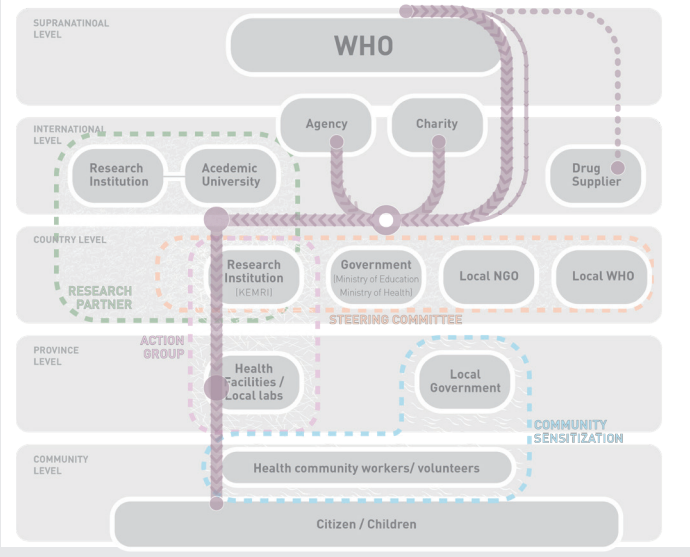
E. Diagnostic related data:

Diagnostic-related data can be considered as one of the most critical data, as it concerns the determination of the controlling situation of Schistosomiasis. Based on the standard approach to diagnose Schistosomiasis, microscopic egg count is 10ml of urine; it is vital to record the amount of urine, the appearance of urine, occult of urine, and of course the amount of Schistosoma eggs that are found, as well as the time and date of the testing. According to the situation in Kenya, urine testing happens once every other year (every two years). *Diagnostic related data* is requested by the WHO to monitor the disease. Together with such data from multiple countries, WHO can create an overview of Schistosomiasis controlling worldwide, as well as share the overview to other stakeholders for assessments and research.

F. Parasite related data:

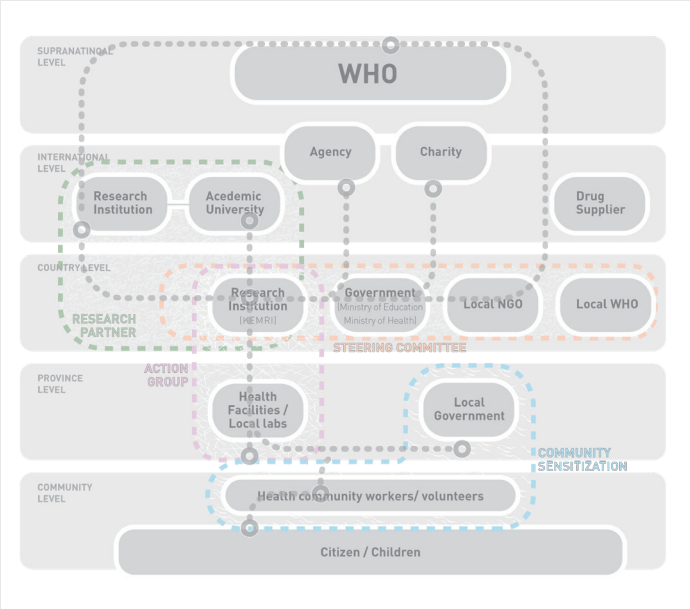
The research of Schistosoma and Schistosomiasis can be rather complex. Depending on research direction, thus, different data will be needed and generated. In terms of the most fundamental *parasite related data*: disease prevalence, parasite taxon, host of the parasite, the intensity of the parasite, and locality of the parasite found are the most common data mentioned for the study of Schistosoma and Schistosomiasis. International research centers comprise the advanced research, which will be shared with local research institutions and WHO for advising on approaches to end the disease. Related parasites will be taken into consideration when field activities (MDA, survey testing) are planned. Advanced researching and advising, as discussed in chapter 3.3.2, do not have a fixed schedule.





G. Resource related data:

Resources act as the most critical aspect that indirectly affects the controlling of Schistosomiasis. As mentioned previously in chapter 1.1, being a neglected disease, the source of supplies, funds, and interest can be relatively limited. Resources will be gathered and managed at the national level. Based on the disease controlling situation reported by the country, WHO will be providing the donated drugs to each country. Stakeholders that support the fighting of Schistosomiasis will also be providing resources in response to the reporting of the controlling conditions, which happens mostly yearly with the occurrence of the MDA.



H. Other data:

Frustrations, advice, opinions, and concerns can occur at all phases from every stakeholder. Meetings and conference may be the most direct way to discover these data. There is currently no shared platform in gathering these qualitative data, as such data can be rough, unpolished, and hard to sort out its interwoven relationships. Despite these facts, answers to hard to solve questions, such as trust issues of citizens and difficulty in promoting policies, may lie in these not yet codified data.

5.3 Gaps and drawbacks -- The implied hint to geared up digital data effectiveness

As mentioned in chapter 1.2, immediate update and rapid synchronization make digital data "alive." With the advance of technology, the lively and flexible aspect of digital data empowers people to make "need" a priority, instead of communicational constraints. Following are the four problems identified from the research, including the unfulfilled need of stakeholders, blindspots of system, and the shortage of resources (including data as an input). It is inescapable to imagine how digital data can take part in easing these current frustrations. Mainly focusing on how data between stakeholders can be more effectively utilized, these problem definitions pinpointed aspects that are awaiting improvement.

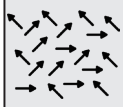
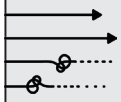
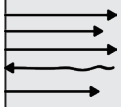
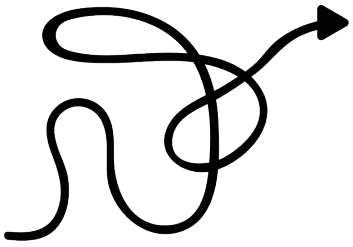
Gaps in the current disease elimination process	Problems statements for the future development direction
A. The directness of data flow	*How to efficiently reroute data streams to increase the directness of data usage and encourage timeliness action?*
 B. The parallel and non-uniform of data flow	*How to overcome linguistic barriers and maximize the number of mutual assistance and learning between different parties?*
 C. Dead-ends in the data flow	*How to improve the quality of the data received, and ensure the completeness of the disseminated data throughout the current disease controlling process?*
 D. Restrictions of data flow due to bureaucracy and regulations	*How to show the effectiveness of diagnostic while not being constrained by the mandated requirements to fit the regulations?*

Table 5-3: Problems statements derived from the gaps seen in the mapping.

Below is a further explanation of each frustration in the current disease elimination process:

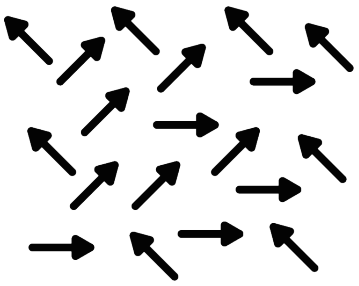
A. The directness of data flow



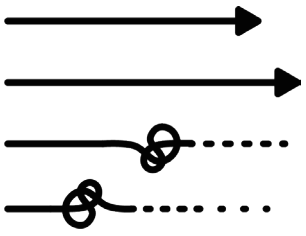
a) Scattered resources and clearly defined duties create a lot of bureaucratic steps for the authorization approval of drugs receiving, MDA performing, samples processing, funds gathering, results reporting, and even technician recruiting. Clear division of powers and functions can not only create a stable structure in the system but also may cause an onerous and long process that reduce efficiencies, which can limit the disease combating approach.

b) The communication flow is indirect and not straight forward. Despite having the common goal of detecting, preventing, and controlling the epidemic of Schistosomiasis, communication between stakeholders may be rather complex due to their ambit of power and responsibility. An example will be a time delay for international research institutions to communicate and advise the local field. Annual reports (per year) from epidemic countries are currently the main channel for international research institutions to conduct analysis. Through advising WHO in planning roadmaps and strategic approaches, international research institutions may give views on actions to be taken. However, the WHO guideline takes ten years intervals to be updated.

B. The parallel and non-uniform of data flow



a) Data collection is done through multiple channels: international research institution, local research institutions, charities, universities, agencies, etc. Each of the parties has its purpose for collecting the data; thus, it is hard to integrate and compare information between different streams. The coherence and synergy in the sharing of data, information, and knowledge can be further strengthened.

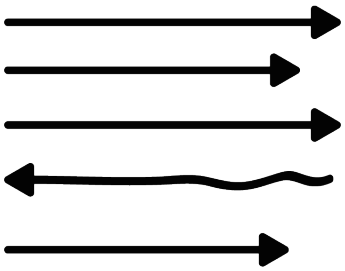


C. Dead-ends in the data flow

a) With the current controlling approach and information exchanging situation between stakeholders, data that are considered as unnecessary are more likely to be left out. An example of data being lost or overlooked would be the information with the details of a citizen on the individual level. Due to the nature of MDA (mass drug treatment to everyone despite Schistosomiasis positive or negative)

and the dependence on limited resources (budgetary constraints make individual testing difficult in practice), the feedback or data from a citizen may only end up between the local citizens themselves and the community workers that have their trust.
This phenomenon may not be that much of an issue in the short-term, but may inadvertently eat away potential information that could give insight to long-term strategy improvements.

D. Restrictions of data flow due to bureaucracy and regulations



a) Downsides of WHO's overarching framework.
The guidelines provided by WHO to overcome Schistosomiasis formulated the parameters in planning, diagnosing, monitoring, etc. Countries are requested to show the drug coverage of children treated (the percentage of "mass" drug administration). This universal criterion has a chance to adversely affecting the performing other disease elimination approach (ex: The "Mass Examination" approach which is firmly believed by a group of experts), as meeting the request standard of WHO is of importance. The phenomenon of "exchanging report with resources" may minimize the chance of trying out other long-term solutions that do not instantly and directly show the effect.

b) There is a limited way to sufficiently prove the effectiveness of resources spent on Schistosomiasis. To receive drugs and funds for next year, "figures" of the disease prevalence and drug coverage is currently the most common way to show the results. Depending heavily on the result-feedback-channel of "reporting" can easily weaken the importance of this neglected disease. For example, in comparison with projects like construction and agriculture in low-resource settings countries which are also funded, it is easier for these projects to showcase the results of funding by pictures or by witnessing the changes with one's own eyes. Thus, it is more likely for those projects to receive assistance, and get passed through the budget audit procedure compared to the project of Schistosomiasis.

5.4 Conclusion

> ***Data*** *are symbols that represent the properties of objects and events. Information consists of processed data,*
>
> ***Information*** *is contained in descriptions, answers to questions that begin with such words as who, what, when, where, and how many.* ***Knowledge*** *is conveyed by instructions, answers to how-to questions.* ***Understanding*** *is conveyed by explanations, answers to why questions.*
>
> *Information, knowledge, and understanding enable us to increase efficiency, not effectiveness.*
> '
>
> *-- <From Data to Wisdom>, 1989 Russell Ackoff*

From recognizing players in the field, understanding their offering, creating an overview via the commonly used data, adding in the layer of time and information flowing direction, to capitalizing the hidden opportunities for future improvements, via these series of graphs, the researcher demonstrated how data in the elimination of Schistosomiasis are used and further transformed into useful information and knowledge.

Based on the systematic analysis of the previous two chapters, the researcher has formulated and composite a holistic and comprehensive overview. With "data" being the major role of discussion, individuals can understand how data were processed into information by answering the following WWWWWH with a logical view:

1. “Why” a certain type of data is needed?
   (The motivation behind the craving of certain data)

2. “What” data is needed, and what data is missing?
   (What data can be further created?)

3. “Who” can best leverage important data?
   (Which stakeholder in the key to making changes?)

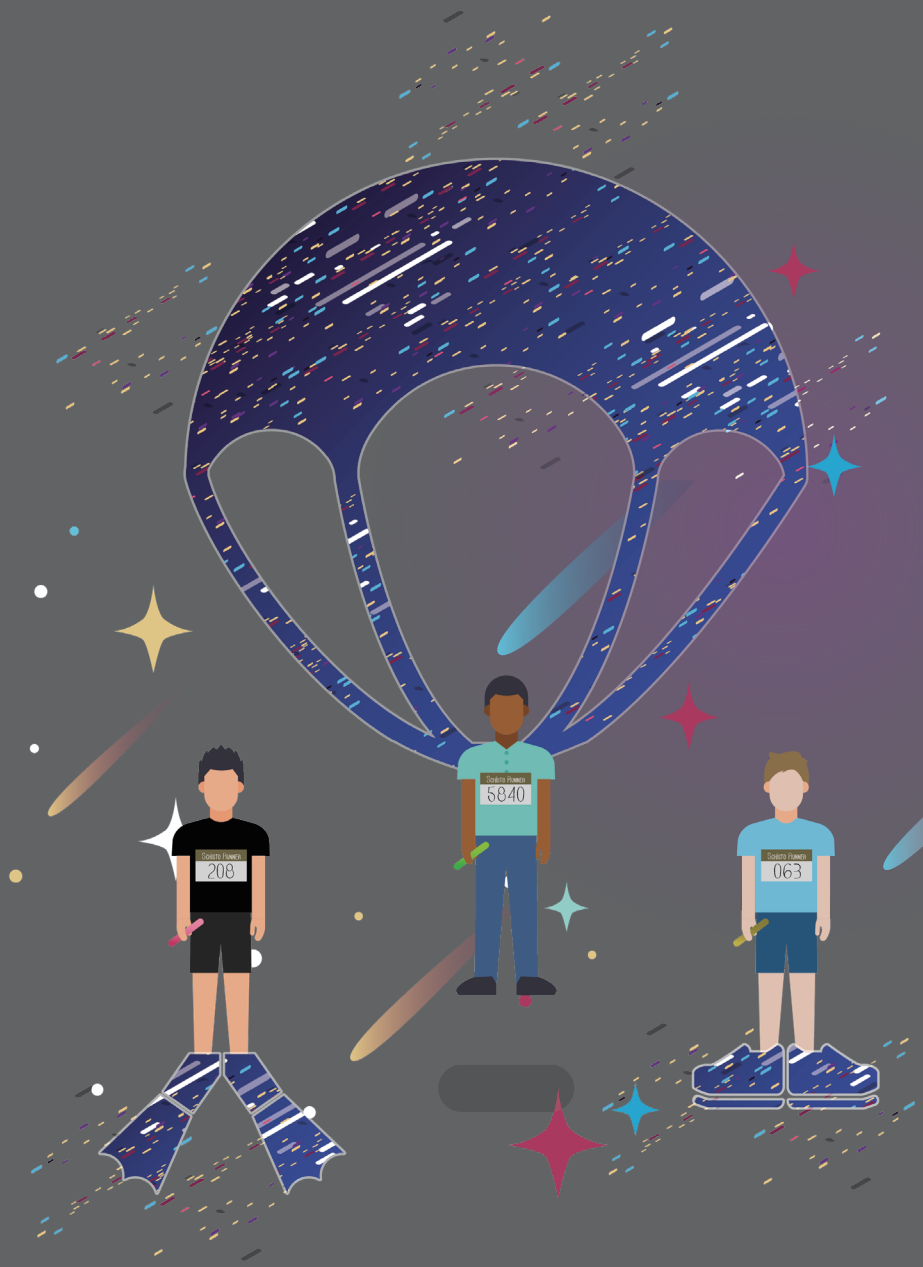
4. “Where” to find the missing piece of data?
   (Where should changes be made to?))

5. “When” should the flowing of data best takes place?
   (How should the creating of a data best happen?)

6. “How” should stakeholders strike a balance between "pragmatically using the existing data" and "proactively creating new data?"
   (How should new intervention be made in the existing picture?)

From data to information and from information to knowledge, the context presented in the above chapter (ex: Figure 3-2, 3-3, 4-3, 5-2, and table 5-3) are expected to act as a tool to assist people with aspirations of making changes in understanding the current situation around them and to further make strategic decisions for their next step.

To demonstrate the use of these graphs (/maps) introduced in chapter 2, 3, and 4, in the following chapter, the future developing direction of the newly developed diagnostic device, SODOS, will be presented as an exercise to demonstrate how the research approach can be used as a tool to provide future development directions.



Digital technology "boosts" the ability of ~~stakeholders~~ runners and is expected to create a new phenomenon in the transferring of ~~data~~ relay batons!

6 Application of the untapped digital data mapping - SODOS

The comprehensive view presented through the previous chapters has pointed out the way forward in the improvement of ending Schistosomiasis disease. From the indirectness of data transferring, ununiformed documentation of information, silo data stream in the system, and regulation process that sacrifices the efficiency ... all these phenomena of drawbacks give digital-health-devices a chance to prove themselves.

To showcase the effectiveness of this research, and to give direction to these ambitious innovators in AidX, in this chapter, SODOS will be assessing its current product feature with the insight received from the mapping of stakeholders value and data footprints. A direction for sustainable intervention is expected.

** Guidance: For Practical Use >>*

With the example of SODOS, people with the intention to participate in this innovation via data are all invited to reflect on their project step by step along with SODOS.

6.1 The smart optical diagnostic device - SODOS

SODOS is created for diagnosing Urinary Schistosomiasis. Unlike the most common diagnostic method used in the field, manual microscopy egg count, SODOS identifies the parasitical egg of Schistosoma by automatically capturing holographic images. Together with cameras without lens, a laser diode casting light through urine samples will create images of Schistosomiasis eggs when the urine sample flows through the designed channel.

The design of SODOS is created to fit with the current WHO Schistosomiasis controlling guideline, including the suggested amount of urine, the expected throughput for the school-based deworming program, and the environmental situation of the most common diagnostic providing location.

Aside from the egg identification and calculation that is automatically controlled by an internal Raspberry Pi (small single-board computers), the data captured by the device will be automatically stored in the SODOS server, which allows instant monitoring and seamlessly access to the captured data.

Image 6-1: the new diagnostic device SODOS (Photo credit: ©2019 Max Hoeboer)

6.1.1 Unique product features

[Lower the threshold for diagnosis]

An easy learning curve for technicians
- Highly automotive, Few manual steps
- Humane designed
- No need to prepare samples

Lower production and operation cost
(in comparison with microscopy egg count)

Location flexibility
- Low electric power needed

[Higher diagnosis result in quality]

Allow real-time data reporting & distance monitoring
- Server storage automatically
- Fast and efficient in generating a result
- Digitize data automatically

Sensitive to light infections
- Low chance of errors and misdiagnosis
- Low chance of sample contamination

Additional image capturing

Table 6-2: the unique product feature of SODOS: 1) the lowering of diagnosis threshold. 2) higher diagnosis result quality

Following the past practice of Urinary Schistosomiasis survey testing for disease prevalence and the School-Based Deworming Programme, urine samples will be collected from the school. Each urine sample is set to be 10 ml, according to the WHO guideline. From this stage, the new innovative diagnostic from SODOS is used. Instead of transferring these urine samples in dark containers within a short amount of time to the closest lab for manual microscopy egg-count, the diagnosis can be examined on-site automatically with the help of SODOS.

With the syringe carrying the unprocessed 10 ml urine samples, the automatic syringe system of SODOS will push the sample through a special slide for the capturing of holographic images. The egg of the Schistosoma parasite will be identified via this process.

The number of eggs will be calculated and translated into the disease prevalence of the epidemic area after all samples are processed.

The examine process can be done easily and automatically. With the current SODOS model, manual steps are still required in the loading and unloading of samples, including the simple rinsing of the equipment. However, compared to the standard microscopy diagnostic method, which required high-skilled technicians to process the samples, SODOS eases the effort of manpower recruiting, and lowers partnership dependency with medical labs, as it is operable without medical knowledge.

SODOS can be fully operated with low power provided by a single power bank. The essential component of SODOS (laser diode and camera without lens), diagnosing via holograph images, can be easily replaced into an affordable model.

SODOS is highly sensitive to the detection of light infections. Compared to other methods in rural conditions, this can be considered the most significant specialty of SODOS, which can aid in breakout prevention.

Controlled by an internal raspberry pi, the generated result (image of parasite eggs, and the number of eggs) will be sent automatically onto the SODOS server. The result from all devices can thus be monitored from a distance through the platform of SODOS.

The unique product feature of SODOS can be broadly categorized into the following two groups: 1) the lowering of the diagnosis threshold. 2) higher diagnosis result quality (see Table 6-2).

6.1.2 Comparison between SODOS and other methods

The list in the table 6-3 is SODOS together with the most common procedures of Schistosomiasis detection.

Microscopy egg count, as mentioned previously, is the standard method suggested by WHO. The diagnostic method is done by manual counting of eggs via the lens of a microscope. Since the processing of microscopy egg count is already mentioned in Chapter 1.1.3, it will not be repeated here. In sum, even though microscopy egg count can be weak in the detection of light infection, the overall rating of cost, throughput and accuracy still make microscopy egg count a very useful method for examination within high and medium disease prevalence.

The *Schistosomiasis questionnaire* is the other commonly seen diagnostic method in rural conditions. An example of a questionnaire can be seen in image 6-4. Body sample (urine or blood) is not required in this diagnostic method. Through the questionnaire,

the symptom of Schistosomiasis will be questioned. With the answers from school-aged children, the disease prevalence will then be judged. Although the Schistosomiasis questionnaire is possible to achieve high throughput, the resulting quality can be low, as it is done by check-list instead of the professional medical diagnosing process. "Do you have blood in your urine" is the key question of Schistosomiasis questionnaire. However, hematuria (having blood in urine) can at the same time reflect several possible body issues such as inflammation in the kidney, urethra, or rhabdomyolysis, which can make the diagnosing for Schistosomiasis insufficient.

Diagnostic via *Antigen* and *Polymerase Chain Reaction (PCR)* is also another option for diagnosing Schistosomiasis. However, the expensive equipment and the low throughput in diagnosing restrict the usage of these two approaches in rural epidemic areas.

Antigen diagnosis is often used in rapid diagnostic testing (RDT). A reagent strip assay detects the circulating cathodic antigen (CCA) in the urine or blood sample of patients. A urine sample can be collected easier compared to blood samples; however, blood samples can be more sensitive to light infections (Gryseels, 2013). Being gene-specific, 'antigen testing' will only be able to diagnose whether the patient has a Schistosoma parasite in the body, instead of the type of Schistosomiasis (as there are five types of Schistosomiasis). This issue makes antigen testing also less useful in areas with several parasite infections (Poldermaan, 2005).

PCR identify parasite DNA via urine samples. Examining via DNA makes PCR highly sensitive for light infections, as eggs may not be presented in the urine. This makes

** Guidance: For Practical Use >>*

[Function Analysis]

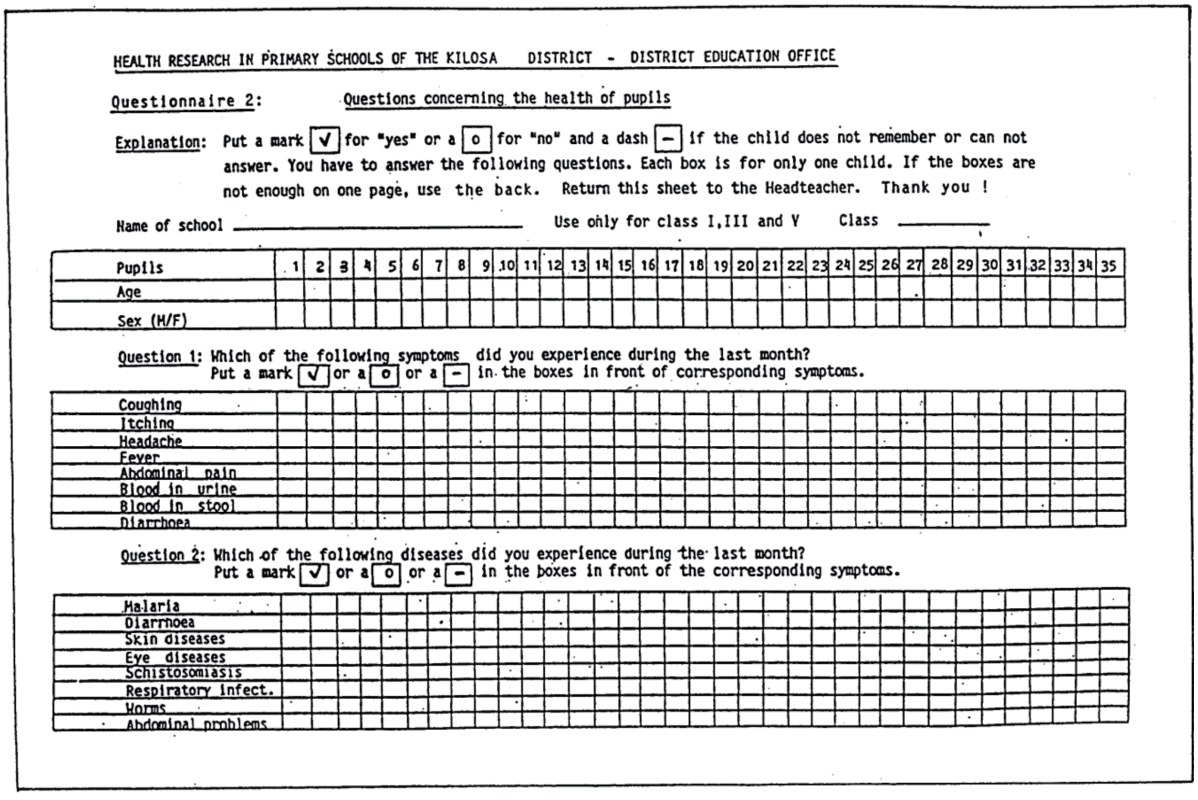
Having a clear understanding of the strength and special features of your innovative intervention is an important first step. Try to think of the following: How will you describe your idea in terms of functions and sub-functions, without describing features such as shape, material, and dimensions? What is the fundamental intention that you were aiming to achieve with your innovation, and what makes it possible to do so? (Roozenburg, 1995) It may be easier to try to describe the function by a verb and an object (noun) (Van Boeijen, 2014).

Write these specialties down. Prioritize them in uniqueness, cluster the similar ones, and categorize them reasonably. Finally, bring them to an abstract level by titling them (e.g., as seen in the case of SODOS: "Lower the threshold," "Higher diagnosis result").

This step helps separate the wheat from the chaff, set the identity, and polish your good intention towards a creative breakthrough.

	Channel	Cost (per patient) (Le, 2017)	Skills required	Throughput	Environment flexibility	Accuracy (sensitiveness)	Drawbacks / Remarks
SODOS	urine	Medium	Medium-low	High	Flexible	Medium-high	- A device created only (specifically) for diagnosing Schistosomiasis
Microscopy Egg count	urine	Medium (1.00 $)	Medium	Medium	Not Flexible	Medium	- Not sensitive to light infection - Manual error possibility
Questionnaire	x	Low (0.05 $)	Low	Highest	Flexible	Low	
Antigen	blood / urine	High (3.00–3.15 $)	High	Low	Not Flexible	Highest	- blood samples are not easily collected but can be more specific. - Gene-specific, can not differentiate the species of Schistosoma
PCR (Polymerase Chain Reaction)	urine	Highest (6.40–7.70 $)	High	Low	Not Flexible	High	- detect early stage of infection

Table 6-3: the comparison of SODOS together with the most common procedures of Schistosomiasis detection



HEALTH RESEARCH IN PRIMARY SCHOOLS OF THE KILOSA DISTRICT - DISTRICT EDUCATION OFFICE

Questionnaire 2: Questions concerning the health of pupils

Explanation: Put a mark [√] for "yes" or a [0] for "no" and a dash [–] if the child does not remember or can not answer. You have to answer the following questions. Each box is for only one child. If the boxes are not enough on one page, use the back. Return this sheet to the Headteacher. Thank you !

Name of school _____ Use only for class I,III and V Class _____

Pupils	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35
Age																																			
Sex (M/F)																																			

Question 1: Which of the following symptoms did you experience during the last month?
Put a mark [√] or a [0] or a [–] in the boxes in front of corresponding symptoms.

Coughing																																			
Itching																																			
Headache																																			
Fever																																			
Abdominal pain																																			
Blood in urine																																			
Blood in stool																																			
Diarrhoea																																			

Question 2: Which of the following diseases did you experience during the last month?
Put a mark [√] or a [0] or a [–] in the boxes in front of the corresponding symptoms.

Malaria																																			
Diarrhoea																																			
Skin diseases																																			
Eye diseases																																			
Schistosomiasis																																			
Respiratory infect.																																			
Worms																																			
Abdominal problems																																			

Image 6-4: An example of children's questionnaire in Tanzania (Chitsulo, 1995)

PCR valuable in detecting early infections. In comparison with other diagnostic methods, PCR may be the most expensive.

Throughput of the diagnostic method is critical for the school-based deworming program; the required skill of technicians and the flexibility of diagnostic locations are important factors that indirectly limits the performing ubiquity of the method in low-resource settings. The microscopy egg count and Schistosomiasis questionnaire respond better to the field of low-resource setting countries; in comparison, antigen and PCR are mostly seen used in labs for scientific studies.

However, the commonly used method in the rural areas, egg count and questionnaire are both segregated from detecting light infection, which is exactly "the Achilles' heel" especially when the disease is coming closer to elimination. These issues make SODOS competitive when it comes to sensitivity.

In terms of cost, results, and factors, microcopy egg count can be considered the most suitable method for field diagnostics. SODOS will have a completely optimistic future if the cost per diagnostic can be on average closer to or lower than $1.

	Egg count/ 10ml urine	Positive/ total n	Parasite intensity	Prevalence (%)	Parasite antigen	parasitic DNA	Date & Time	Appearance of urine	Symptom of patient	Age	Gender	Location of the patient	Number of eggs in sample	Picture of eggs	Humidity	Temperature	Location of the diagnostic	Diagnostic duration / sample
SODOS	V	V*	V	V			V						V*	V*	V	V	V	V
Microscopy Egg Count	V	V*	V	V			V					V	V*					
Questionnaire							V	V	V*	V*	V	V						
Antigen		V*	V	V	V*													
PCR (Polymerase Chain Reaction)		V*		V		V*												

Table 6-5: the comparison of SODOS together with the most common procedures of Schistosomiasis detection by data collection. (V: Information that can be generated. V: The most critical data for diagnostic)*

It is worth knowing that the diagnostic method of ultrasonography and dipstick are not included in the comparison, as these methods are used to “assist” judgment instead of being designed for specifically diagnosing Schistosomiasis.

Table 6-5 shows the comparisons by data which can be generated by the listed diagnostic method. Bold checks are the most critical data that help determine the result.

As mentioned previously, Antigen and PCR detect the biometric trait of Schistosoma; questionnaire evaluates the symptoms of patients. Both microscopy egg count and SODOS make judgments based on the number of eggs in the urine. The most significant differences between the result generating of SODOS and microscopy egg count is the automatic image capturing of SODOS, which increases the accuracy of judgment.

In terms of location documenting, due to the working principle of SODOS, the current coordinate that can be captured is the location of the diagnostic provided location.

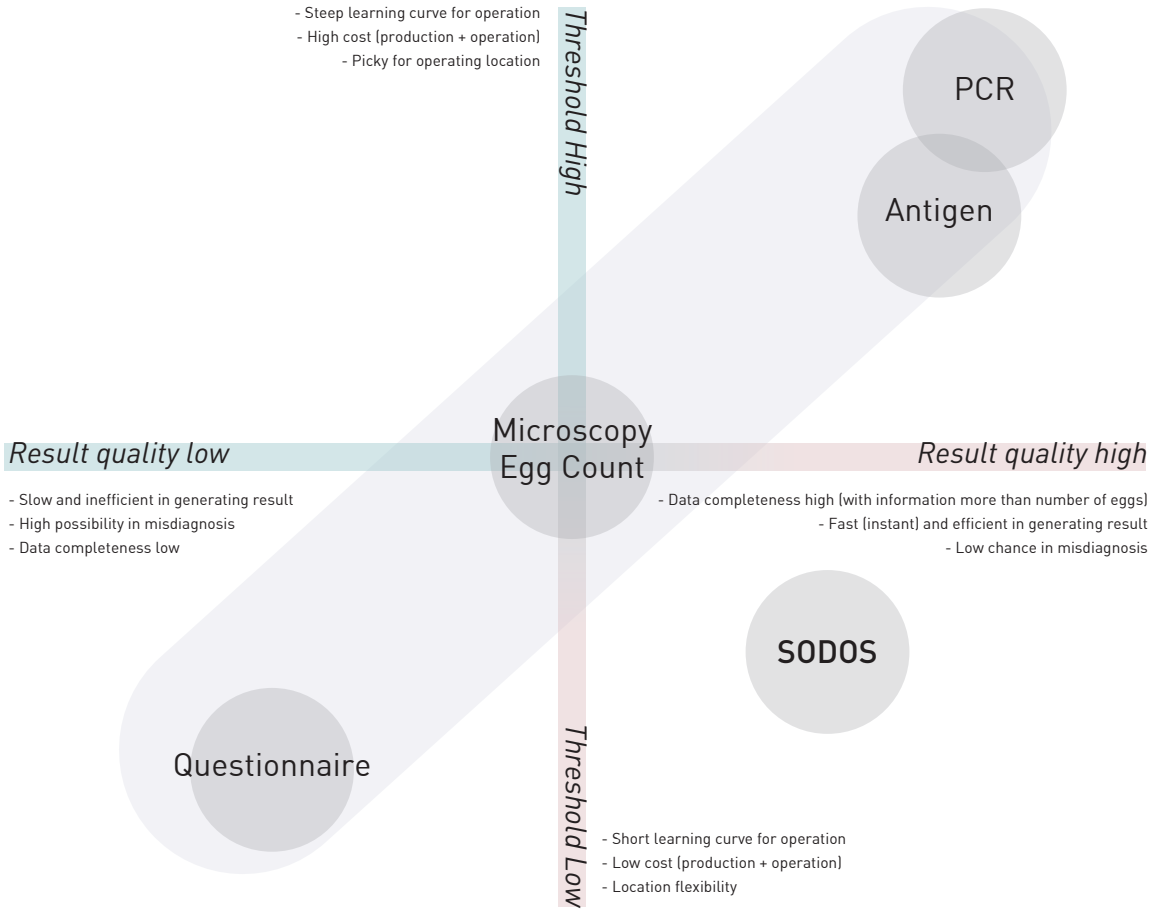

- Steep learning curve for operation
- High cost (production + operation)
- Picky for operating location
Threshold High
PCR
Antigen
Microscopy
Egg Count
Result quality low
Result quality high
- Slow and inefficient in generating result
- High possibility in misdiagnosis
- Data completeness low
- Data completeness high (with information more than number of eggs)
- Fast (instant) and efficient in generating result
- Low chance in misdiagnosis
SODOS
Questionnaire
Threshold Low
- Short learning curve for operation
- Low cost (production + operation)
- Location flexibility

FIgure 6-6: the bipolarity axis of the current urinary Schistosomiasis diagnostic method. The X-axis: the quality of the result; theY-axis: the threshold of performing the diagnosis.

Being done manually, egg count and questionnaire can document the location of patients along with the procedure of diagnosing.

Figure 6-6 puts together the comparing diagnostic method on the bipolarity axis. The subject of axis X and Y are defined based on the unique product features of SODOS discussed in chapter 6.1. The most commonly used diagnostic method, microscopy egg count, is placed in the center of the axis as a benchmark. It is noticeable that the bipolarity axis pushes the current diagnostic method into two groups: low diagnostic threshold with low result quality; high result quality with a high diagnostic threshold. By looking at these two contradictory groups, it is obvious that the lacking characteristic in the current Schistosomiasis disease diagnostic method: High result quality with low performing threshold is where SODOS is located-- a unique competitive position among all the other methods.

** Guidance: For Practical Use >>*

[Competitor analysis]

Competitor analysis is not necessarily the analysis of the competitor, instead, it is an analysis of devices (product, ideas, or service) with the same or similar purpose. In this subchapter for SODOS, the analysis is done through the comparison of diagnostic condition, collected data, and the position in its special features.

Who can be listed for comparison with your innovation? What can your innovation achieve that others cannot? What is the highlighted specialty of your innovation when compared to others? On the other hand, what are the weaknesses of your device?
The direction for determining of your competitor: the level of competition can be categorized into four levels: Form (with similar values and features), Product category, Generic (achieving the same need), and Budget (what can be achieved with the same cost).

Understanding who you are competing can help filter out your strength and weakness, and determine solutions for improvement. A typical SWOT analysis can also be included in this phase if necessary.

6.2 Data-capturing-capability of SODOS

SODOS, a computer (Raspberry Pi) controlled diagnostic device, is able to generate, store, and summarize the collected information. SODOS is a member of the E-Health device. By looking further into the type of generated data, the type of data that can be captured via SODOS can be identified as seen in Table 6-7.

As previously discussed in chapter 4-1, the categories of data that the current SODOS is most capable of generatingare diagnostic related data and reflecting infected area related data.

	Egg count/ 10ml urine	Positive/ total n	Parasite intensity	Prevalence (%)	Parasite antigen	parasitic DNA	Date & Time	Appearance of urine	Symptom of patient	Age	Gender	Location of the patient	Number of eggs in sample	Picture of eggs	Humidity	Temperature	Location of the diagnostic	Diagnostic duration / sample
SODOS	V	V*	V	V			V						V*	V*	V	V	V	V
Microscopy Egg Count	V	V*	V	V			V					V	V					
Questionnaire							V	V	V*	V*	V	V						
Antigen		V*	V	V	V*													
PCR (Polymerase Chain Reaction)		V*		V		V*												

A. Country related data
B. Infected area related data
C. Citizen related data
D. Medical staff related data
E. Diagnostic related data
F. Parasite related data
G. Resources related data
H. (Other)

Table 6-7: The type of data that can be captured via SODOS

Based on the "Infected area related data" discussed in Chapter 4.2- *Purpose of data collection, and* Chapter 4.3 - *Data in each step of the elimination process, the mission of* "Infected area related data" can be seen in table 6-8 and 6-10, including the reason why such data is needed. The stakeholders that are related to this data (either creating these data or needing these data) and the direct influence of this data in such step also can be seen.

Infected area related data reveal the epidemic area, which also reflects the controlling situation. This type of data is generally important throughout the whole Schistosomiasis elimination process, with the first three steps (plan, action, and analyze) being the most highly related.

The same things go for "Diagnostic related data." As discussed in Chapter 4.2- *Purpose of data collection, and* Chapter 4.3 - *Data in each step of the elimination process,* the mission of "Diagnostic related data" can be seen in table 6-9 and 6-11.

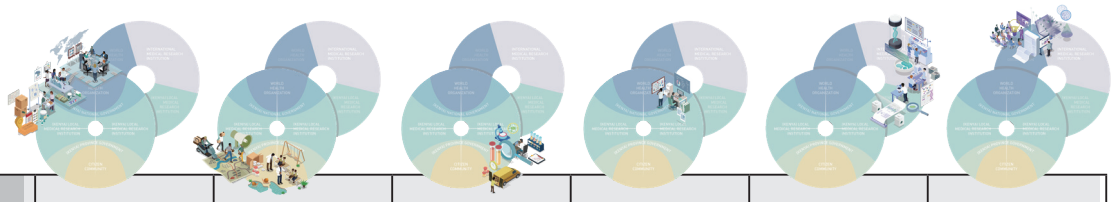
Diagnostic related data appears during and after the analysis phase. Stakeholders in the non-standard data flow (see chapter 3.3.2) also finds this type of data very important. The main reason to generate and collect related diagnostic data is to understand the disease controlling situation, to predict further and advice for improvements.

** Guidance: For Practical Use >>*

[The most 'talented' data]

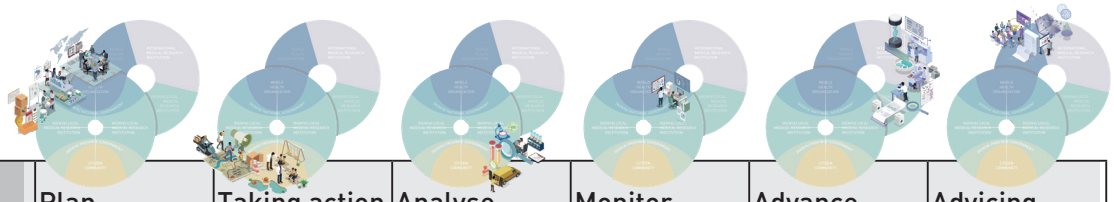
Taking what was previously listed in the competitor analysis (Chapter 4-1), The data that is currently entering the field, as well as the data that can be generated by your innovation, will finally be displayed.

What has the world been needing? How can your innovation contribute to the current demand? What other new things can your innovation bring to the world? The categorized data type in Chapter 4-1 should be able to help reclassify. However, depending on the innovation, the category can be updated with a new category from time to time.



Steps	Plan	Taking action	Analyse	Monitor	Advance analysis	Advicing
Purpose of needing "Infected area related data"	- Allocating resources - Assist decision making - Plan schedule - Distribute jobs - Clearify goal	- To make proper preparation accordingly	- Adjust the approach of diagnostic accordingly	- Compare result in between different years	- Propose direction for improvements - For suitable and customize strategy to each content	- Assist decision making - Clearify goal
Stakeholders that are relevant to this step	- WHO - National government -Local research institution - NGO	- Local research institution - Local government - Community	- Local research institution - Local government - Community - Health facility	- WHO - National government - Local research institution	- Local research institution - Universities - International research institution - Charity / foundation	- Local research institution - International research institution - Global organization
Directness in influencing their work	High	High	High	Medium High	Medium High	Medium High

Table 6-8: the mission of "Infected area related data" in each step of the Schistosomiasis procedure.



Steps	Plan	Taking action	Analyse	Monitor	Advance analysis	Advicing
Purpose of needing "Diagnostic related data"	- To understand the situation	- To make proper preparation accordingly	- Conduct result - Validate strategy planning	- Ensure effectiveness - Monitor progress - Report progress	- Propose direction for improvements - Validate new approach - Pinpoint new problem	- Assist decision making - Clearify goal
Stakeholders that are relevant to this step	- WHO - National government -Local research institution - NGO	- Local research institution - Local government - Community	- Local research institution - Local government - Community - Health facility	- WHO - National government - Local research institution	- Local research institution - Universities - International research institution - Charity / foundation	- Local research institution - International research institution - Global organization
Directness in influencing their work	Medium Low	Low	High	Medium High	High	Medium High

Table 6-9: the mission of "Diagnostic related data" in each step of the Schistosomiasis procedure.

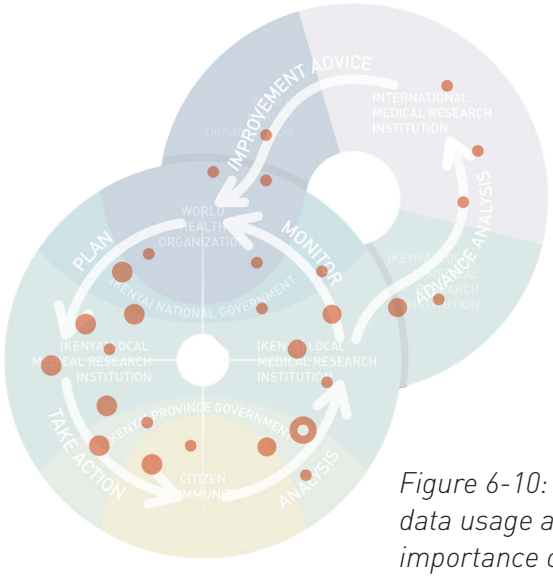


Figure 6-10: The data usage and importance of "Infected area related data"

In summation, with the deeper look into the two types of data that SODOS is most capable of generating, SODOS "most skillful talent," in terms of data, surfaced. As mentioned, SODOS, being an E-health device, can compose these two data into the format of "digital data."

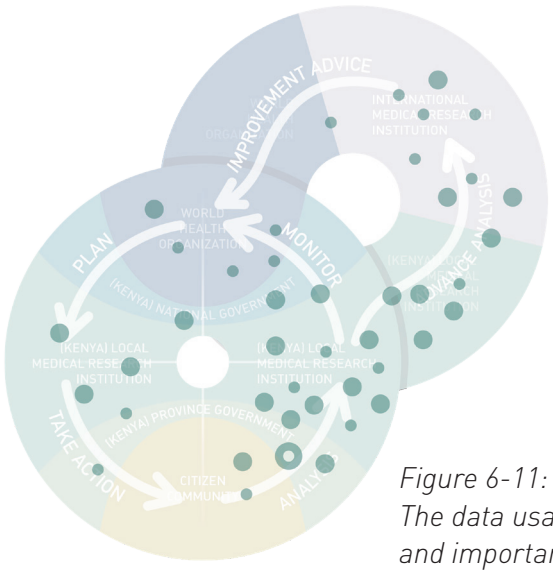


Figure 6-11: The data usage and importance of "Diagnostic related data"

** Guidance: For Practical Use >>*

[The capability of your innovation in data]

After systematically listing how your innovation is different from others, this step helps make you better understand which aspects your innovation can potentially benefit the world.
This step makes use of Chapter 4.2 - Purpose of data collection, and Chapter 4.3 - Data in each step of the elimination process.

Try to search for the following:
Which category of data can your innovation contribute to the most? Who (which stakeholders) are related to these data? How big of influence can you innovation create? What has the world been needing? How can your innovation contribute to the current demand? What other new things can your innovation bring to the world?

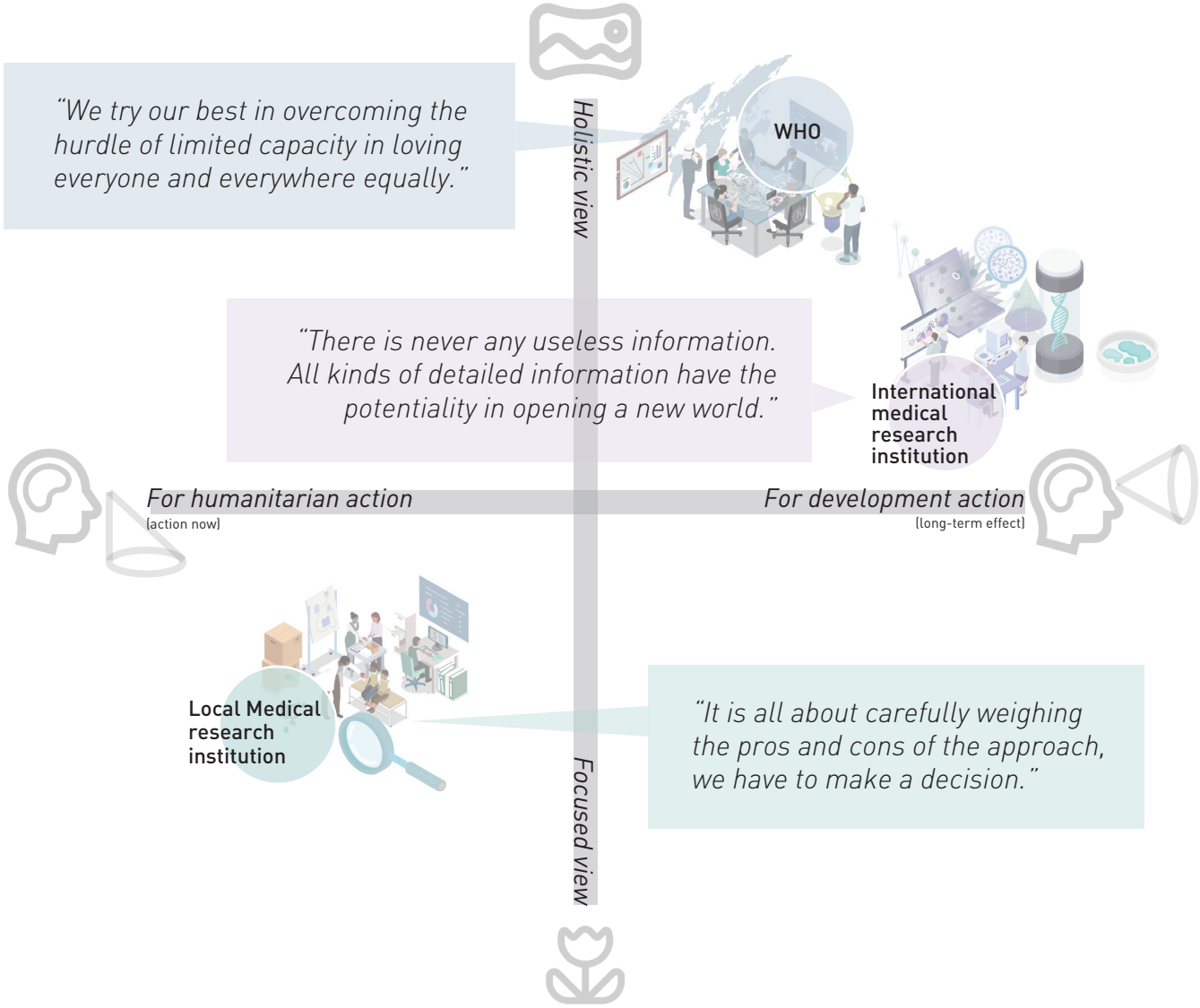
The series of patterned tables in chapter 4.3 should be able to help see the general influence. This step can also be strengthened by conducting expert-interviews with your stakeholders. Further, understand what they can help reflect on your developing direction. Be aware not to force-fit the function of your innovation to their needs, as it can accidentally turn into "innovating for the sake of innovating." Use the needs of these stakeholders as an inspiration for uncovering latent information.

6.3 The potential target audience for SODOS

As discussed in chapter 4: *data are both product and catalyst*. Looking at the box of "purpose for need" and "relevant stakeholders" in the two table of 6-8 and 6-9, data can create influence to stakeholders both directly and indirectly.

Three stakeholders were chosen to be the hypothetical target audience of SODOS by taken into consideration the influencing directness of "infected area related data" and "related diagnostic data:"

1. In terms of influence on practical field action-- Local research institution
2. In terms of influence on depth in the analysis-- International research institution
3. In terms of general impact & influence-- WHO.


"We try our best in overcoming the hurdle of limited capacity in loving everyone and everywhere equally."
Holistic view
WHO
"There is never any useless information. All kinds of detailed information have the potentiality in opening a new world."
International medical research institution
For humanitarian action
(action now)
For development action
(long-term effect)
Local Medical research institution
"It is all about carefully weighing the pros and cons of the approach, we have to make a decision."
Focused view

With the help of the stakeholder bipolarity axis discussed in chapter 3.2: mission and vision, it can see the intention of these potential audiences that can be interested in SODOS (see Figure 6-12). These three hypothetical target audiences all play an important role differently in Kenya's Schistosomiasis elimination procedure.

Each are located in a different area of the axis; they each have a different belief and mindset. Due to a different role, motivation, and responsibility, SODOS can have different meanings to the hypothetical target audience.

To summarize, the three stakeholder's personas are created to discuss their dreams, needs, and frustrations. The source of these personas is from interviews, literature review, conference, and meetings.

Figure 6-12: the stakeholder bipolarity axis of SODOS' hypothetical target audience.

** Guidance: For Practical Use >>*

[Understanding your audience]

Who is your main audience? What is their focusing scope in vision? What is their primary task in mission? How can you "prescribe the right medicine" to your audience and make them fall in love with the new intervention you provide?

Start with the stakeholder bipolarity axis to self-reflect on your decision. Ask yourself: "Do I recognize their mission and vision?" Agreeing with the foresight and philosophy of your target audience can be a fundamental base for longterm development.

Look at the position of these potential target audience and try to imagine how differently your innovation can mean to them. The naming of the polar in X-axis and Y-axis can be changed if necessary.

6.3.1 Target Audience 1: Local research institution

For Kenya, a local research institution plays an enormous role. From planning, action taking, analyzing, to monitoring (see chapter 3.3: *Role and task*). Being an important middleman, the this target audience of SODOS has to put across the assignment of the upper level (WHO, government, and other supporting parties), make sure the planning is carried out in the local community, and constantly strike a balance between "proactive" (as a researcher) and "pragmatic" (as a implementor).

"It is all about carefully weighing the pros and cons of the approach; we have to make a decision."

Ensuring the yearly MDA goes smoothly during the agreed period is one of the highlighted goals for a local research institution. Baseline survey testing for the monitoring and evaluation of neglected diseases is conducted every other year in Kenya. The performance of the elimination planning is also strongly related to the seeking of cooperation and future funders.

Figure 6-13: Persona for the target audience - Local research institution.

Frustration:

- Bureaucratic. lots of waiting, authorizing, reporting...
- Expectation. Expectation pressure from funders
- Budget limitation. Regular and effective diagnostic cost too much, can't afford

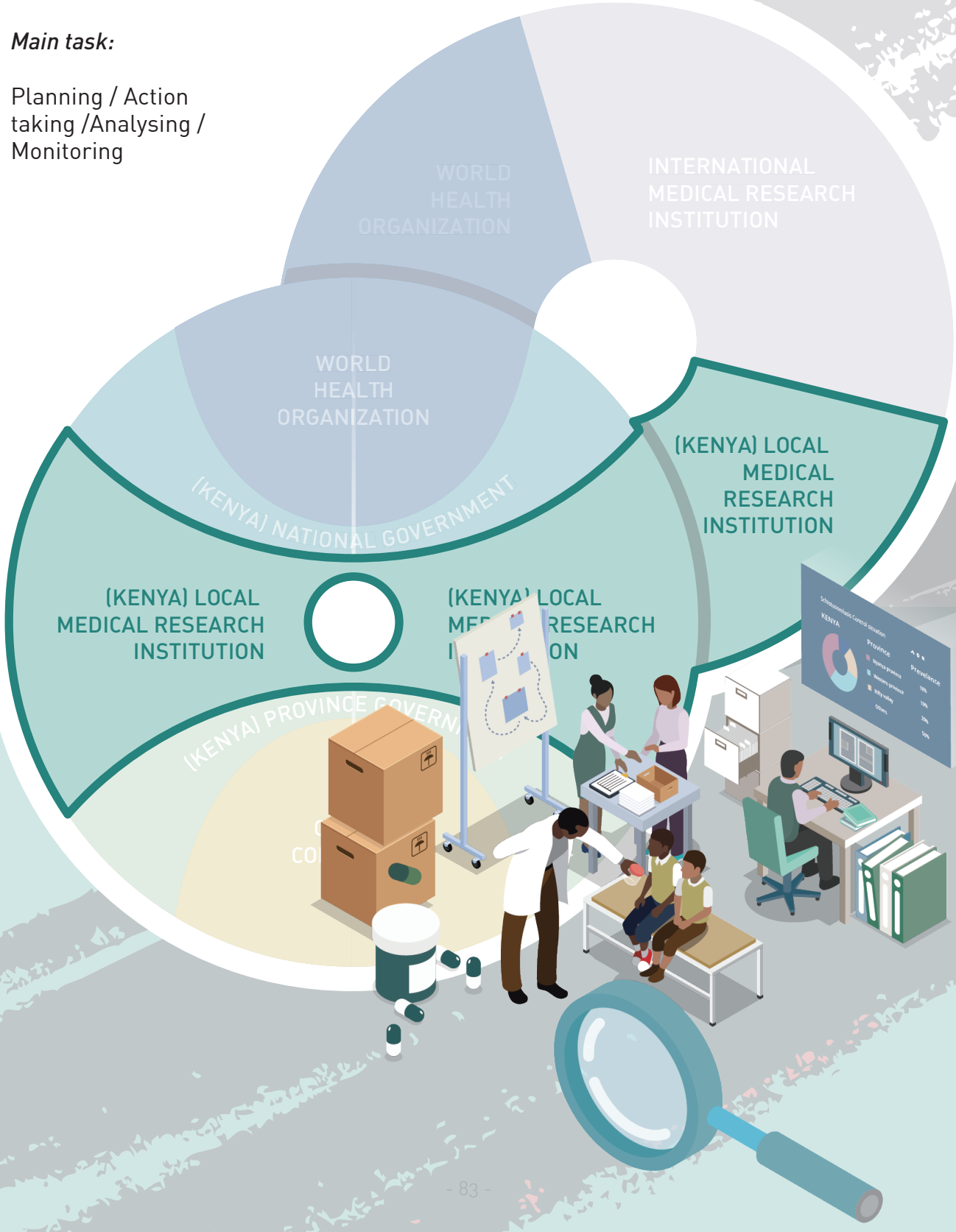
Life (Business) Goal:

- Ensure the MDA session goes smoothly for 5 years.
- Make sure the report show the effectiveness, and can successfully bring in the new funding.
- Supervise creative solution from the university.

Being in such a position, the target audience has to bear the expectation stress from funders and supporters. The task of local research institution can be dependent on authorization, reports, and partnership, as they have a bearing on the success or failure of the elimination.

Main task:

Planning / Action taking /Analysing / Monitoring



SODOS, with its specialty in lower diagnostic thresholds and resulting quality increases, can be beneficial to the local research institution in endemic countries. Figure 6-1 listed the forecasted phenomenon with SODOS' participation.

Local research institution, having most of their role in the standard data flow (see Chapter 3.3.1 : *The left circle: Standard flow*), SODOS can generally bring in the most benefit on easing the stress of catching up schedules, which creates more flexibility for resource allocation.

Figure 6-14: Local medical research institution's forecasted phenomenon with SODOS' participation.

Specialties of SODOS
Lower threshold
The easy learning curve for technicians
- Highly automotive, Few manual steps
- Humane designed
- No need to prepare samples
Lower production and operation cost
Diagnostic location flexibility
- Low electric power needed
Higher result quality
Allow real-time data reporting & distance monitoring
- Server storage automatically
- Fast and efficient in generating a result
- Digitize data automatically
Sensitive to light infections
- Low chance of errors and misdiagnosis
- Low chance of sample contamination
Additional image capturing
(Suggested..)
Data documentation on an individual level

For the development suggestion of SODOS, based on the overview illustrated in chapter 5.1: *Relationship between stakeholders*, the data collecting ability on the individual level is currently missing in the whole process. Even though performing MDA does not necessarily require the individual data of people, this information can help look into the aspect of culture and behavior. (for further understanding, see chapter 5.2: *The flowing of data and information, C. Citizen related data*)

What new phenomenon can be seen with these benefits of SODOS

- Ease the effort in recruiting technicians
- Lower cost in diagnostic & analysis

- Provide mass examination to everyone instead of mass drugging.
- Provide more flexibility in the usage of funding resources (ex: Allow the government to distribute limited funding resources amongst all epidemic areas and regions.)

- Ease the time pressure between sample collecting and analysing.
- Possible to conduct on-site analysis right after the samples are collected from the patients.

- Possibly easing the stress in bureaucratic paper reporting.
- Make this 'neglected' disease more 'visible' in terms of data (information) transparency improvement.
- Encourage the chance of "comparing result" between different regions and countries.
- Finally being able to validate "true elimination".

- Being able to show the citizen the eggs of Schistosoma parasite for what it really is.

- Being able to trace and track the individual.

6.3.2 Target Audience 2: International research institution

In the scope of the research, the international research institution is the representation of the non-standard data flow (see chapter 3.3.2: *The right circle: Non-standard flow*). The target audience of SODOS does deeper analyzing with the information from the epidemic region and the field of science. Advising WHO and the local research institution is also another important task of international research institutions. Working in the present, while thinking for the future, their task can be diverse. However, unlike the previous target audience, there is less routine work for them; instead, the project varies from time to time.

"There is never any useless information. All kinds of detailed information have the potentiality in opening a new world."

The business goal of international research institutions includes advising on the optimization of the controlling program. Advising may be done through assisting WHO in future roadmap planning, or directing the approach of epidemic countries.

However, as also can be seen in chapter 5.1: *the relationship between stakeholders*, with a majority of data source coming from the disease prevalent countries, their working

Figure 6-15: Persona for the target audience - International research institution.

Frustration:

- Highly dependent on each country's annual reports.
- The advice (to WHO) takes time to be truly embedded in the field.

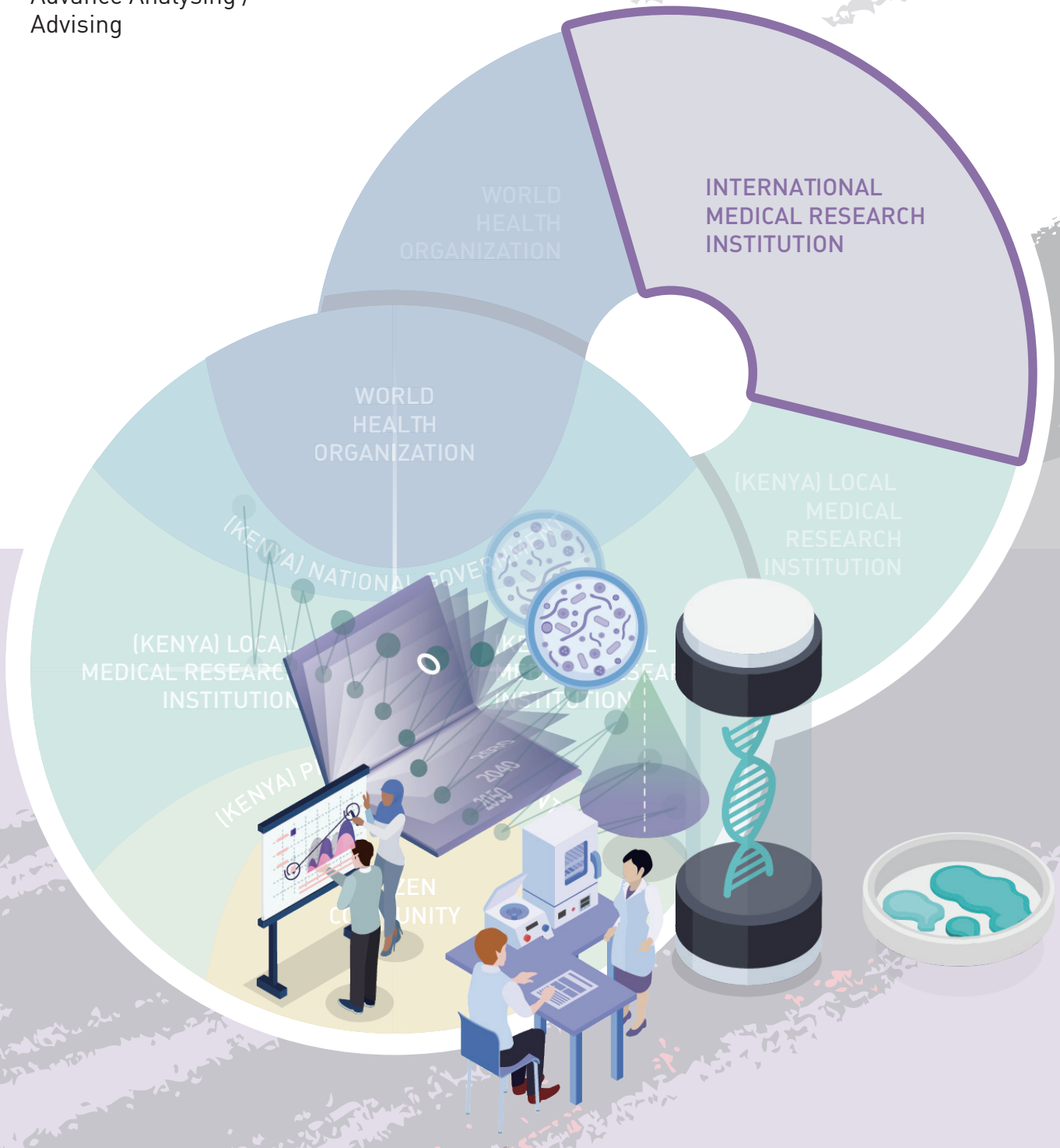
Life (Business) Goal:

- Give optimized advice for future disease controlling approach.
- In some extent predict the future with the change of the new approach.
- Act as a strong assistant in stirring the direction of disease controlling process.

progress is strongly dependent on annual reports conducted by each country. In the role of advisor, the target audience of SODOS has less control in the implementation time frame. Very often, the advice they provide will have to go through WHO's long-term planning, which takes years before it can be implemented.

Main task:

Advance Analysing /
Advising



Being outside the epidemic area, an international research institution can be influenced by SODOS in a very different way compared to the previous target audience. Figure 6-16 lists the forecasted phenomenon with SODOS' participation.

The first special characteristic of SODOS, lowering the diagnostic threshold, may not influence the target audience. However, high-quality results can mean a lot. Being often far from the disease prevalence area, rapid updating, distance monitoring, and image capturing of the parasite eggs can enrich the data source of these data-craving people. SODOS has the potential for expansion of research diversification for international

Figure 6-16: International research institution's forecasted phenomenon with SODOS' participation.

Specialties of SODOS
Lower threshold
The easy learning curve for technicians
- Highly automotive, Few manual steps
- Humane designed
- No need to prepare samples
Lower production and operation cost
Diagnostic location flexibility
- Low electric power needed
Higher result quality
Allow real-time data reporting & distance monitoring
- Server storage automatically
- Fast and efficient in generating a result
- Digitize data automatically
Sensitive to light infections
- Low chance of errors and misdiagnosis
- Low chance of sample contamination
Additional image capturing
(Suggested..)
Data documentation on an individual level
Being able to control the item of data collection items from distance through program updating

research institutions.

For the development suggestion of SODOS, during interviews, the target audience also mentioned the missing of citizen's data. Projects like drug adherence, reinfection, and drug resistance can all be related to the collecting of the currently missing data. SODOS, as an e-health device, can select 'the collected data' which may become another interesting feature to these far-distance stakeholders. Wisely selecting the collected information can, on the one hand, fulfilling the need for research and monitoring, and on the other hand, help reduce the time of SODOS' sample processing procedure and increase diagnostic throughput.

What new phenomenon can be seen with these benefits of SODOS

- n/a
- n/a
- Getting data input from parties outside health facilities.
- Free the research procedure from the reliance on paper reports.
- Allow new insights to be discovered based on the zero time difference in monitoring.
- Allow new insights to be discovered through comparing-result between different regions and countries.
- Having a chance to make instant advising.
- Allow insights for "light infection in low resource settings" to be discovered. (Ex: the relationship between light infections and drug resistance.)
- A chance to discover different information from the urine sample.
- Additional material for further research in a broader view
- Being able to trace and track an individual for new insights for projects.
- A channel for real-time data collection in correspondence to requested projects and new approaches.

6.3.3 Target Audience 3: WHO

Last but not least, the most holistic target audience, is WHO. The potential target audience of SODOS plays an important role in all health-related topics all over the world. With their official vision being "To build a healthier world for everyone and everywhere," they held conferences, compile future planning, advice practice, promote awareness, and encourage people with the intention that aligns with their organizational belief. Their task can be broad. For WHO, a big part of the challenge lies in the varied level of development in different countries.

"We try our best in overcoming the hurdle of limited capacity in loving everyone and everywhere equally."

In the case of Schistosomiasis elimination for Kenya, WHO takes part in the phase of planning, monitoring, and of course, advising in the practical approach. WHO review the elimination result of epidemic countries, interfere if necessary, and plays a credible, authoritative, and reliable backbone for health-related activity.

Figure 6-17: Persona for the most holistic target audience - WHO.

Frustration:

- Setting guideline is one thing, but implementation is another.
- Want to work fast and wit like a cat in acting flexible to changes, however we are more like a big tortoise... we make great and steady steps but we can't speed up.

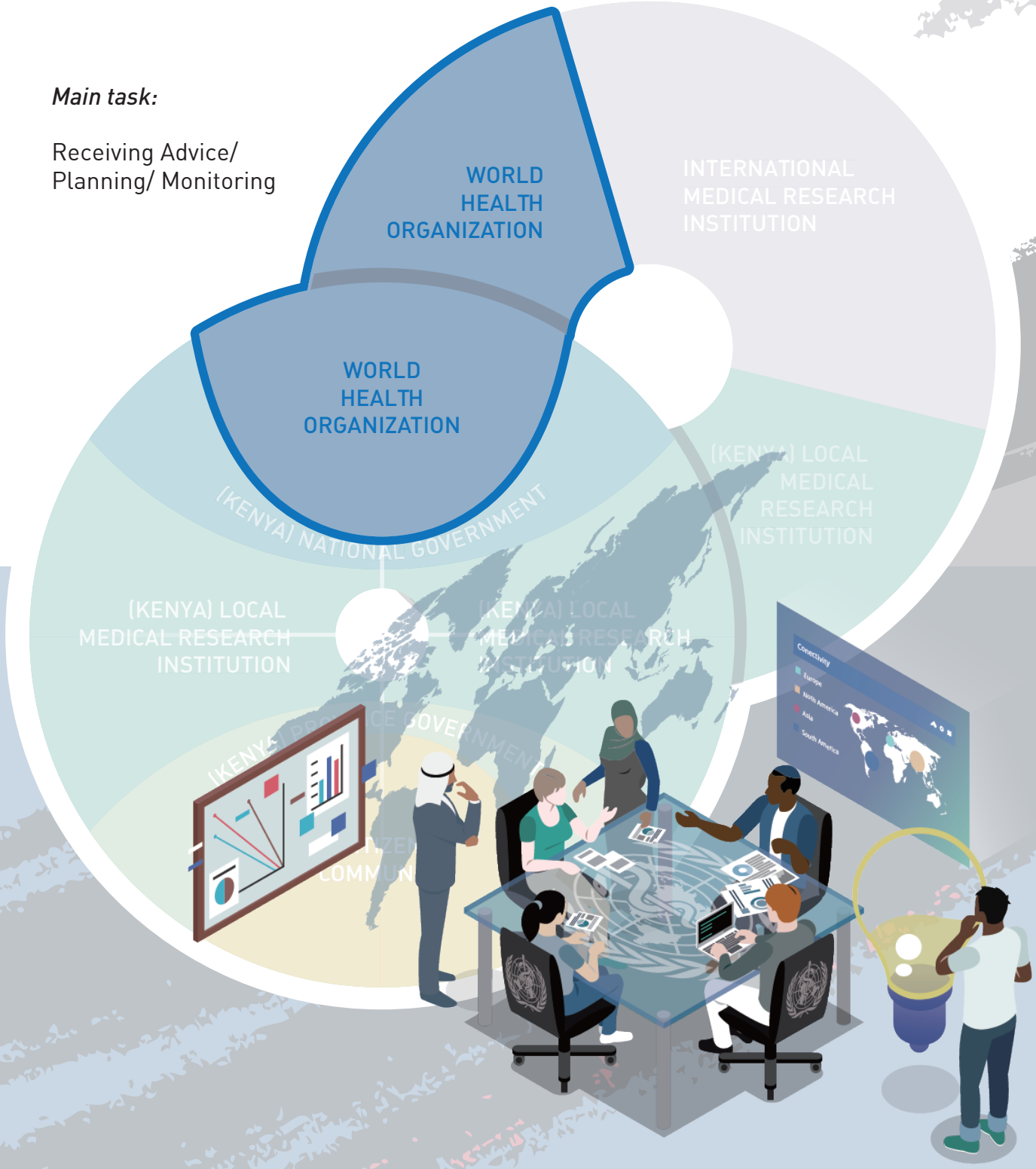
Life (Business) Goal:

- Summarize expert advice for future disease controlling approach.
- Held events and activities to unite countries, draw awareness, and brainstorm for future.
- Act as a credible, authoritative, and reliable backbone for health related topics.

Playing a leading role, the target audience of SODOS has a double burden of thinking big while thinking practical. Every announcement and action made by WHO has to be carefully deliberated, as it could have a significant impact. For the target audience, it is hard to be agile. As it can be seen in chapter 5.2: *Flowing of data and information*, WHO are the terminus of lots of data stream. It is important for WHO to make the best use of the collected information.

Main task:

Receiving Advice/
Planning/ Monitoring



Bearing high privilege and heavy responsibility, SODOS can broaden its influence together with WHO. Figure 6-18 listed the forecasted phenomenon with SODOS' participation.

The most benefit SODOS can bring to the holistic target audience is better management and governance of the disease. For WHO, the low threshold can help bring their good intentions to all corners of the world. SODOS' specialty in high-quality results can assist with systematic control from a distance, help set up a complete database for

Figure 6-18: WHO's forecasted phenomenon with SODOS' participation.

Specialties of SODOS
Lower threshold
The easy learning curve for technicians
- Highly automotive, Few manual steps
- Humane designed
- No need to prepare samples
Lower production and operation cost
Diagnostic location flexibility
- Low electric power needed
Higher result quality
Allow real-time data reporting & distance monitoring
- Server storage automatically
- Fast and efficient in generating a result
- Digitize data automatically
Sensitive to light infections
- Low chance of errors and misdiagnosis
- Low chance of sample contamination
Additional image capturing
(Suggested..)
Being able to control the item of data collection items from distance through program updating

the study of disease, and furthermore, with its top-down approach, trigger more people to rack their brains for the progressive development of eliminating the disease.

Since the required time for new interventions has always been taking a long time for WHO, for the development suggestion of SODOS, the remote 'data collection controlling' can be an interesting feature for SODOS to look into additionally. Being able to monitor the result rapidly, this ability to do "distance data collecting changing within a short time" can help WHO in being agile while inlining with the local circumstances.

As discussed in chapter 5.3: *Gaps and drawbacks*, SODOS has a chance to fix or ease these issues. In the next chapter, the researcher will examine how SODOS can change or improve the current data flow as a whole with these three hypothetical target audiences.

What new phenomenon can be seen with these benefits of SODOS

- Less personnel and inspector needed to send into the field.
- Provide more flexibility in the usage of funding resources
- Flexibility in guideline suggestion
- Knowing what can be expected for the disease prevalence, and can put more effort further on when, where, and how elimination planning can improve.
- Free the controlling and managing procedure from the reliance on paper reports.
- Being able to control, manage, and combine new insight globally.
- Being able to monitor what is still under process instead of waiting for the result.
- Allowing validation for an elimination strategy.
- Being able to set up a more complete profile for Schistosomiasis
- Increase distance controlling ability

** Guidance: For Practical Use >>*

[Stakeholder persona & influence estimation]

A persona can be useful in summarizing and communicating the findings. By modeling a quote that sums up what matters the most, thinking of their ultimate goal, as well as their frustration while doing their job, it will be easier to guide you and your team into their shoes, and better create values that they may find useful.

For the estimation of your influence, place the special characteristic of your innovation (those you've analyzed previously) on the left, and go through them one by one. Think of how it can be used and why it may be interesting to your audience. Having a good understanding of your target is critical in exploring this influence estimation.

It can be interesting to invite your potential target audience in doing this brainstorming together. Forget your innovation for a while. Without giving too much detail explanation of your innovation (to avoid bias and limitation for imagination), listen to what they say, ask them to imagine a world without any restraint in the budget, technology, and any other barriers. "What will your job be like if anything is possible? Unlimited money, no language barriers, advance technology ..., what is your dream world like?" These kinds of conversations can help you think wild. If possible, illustrate these answers into visuals, and with the list of special characteristics you made for your innovation, reflect: To what extent my innovation can help them in being a step closer to their ideal vision?

6.4 How will SODOS possibly change or improve the current data flow

In the previous chapter, the hypothetical target audience was individually discussed from the points of view of practical influencers in the field (local research institution), parties for diverse advance analysis (International, research institution), and the leader of the global health sector (WHO). In this chapter, the researcher will elaborate on how SODOS' influence can be maximized if all the target audiences successfully implemented SODOS in their work.

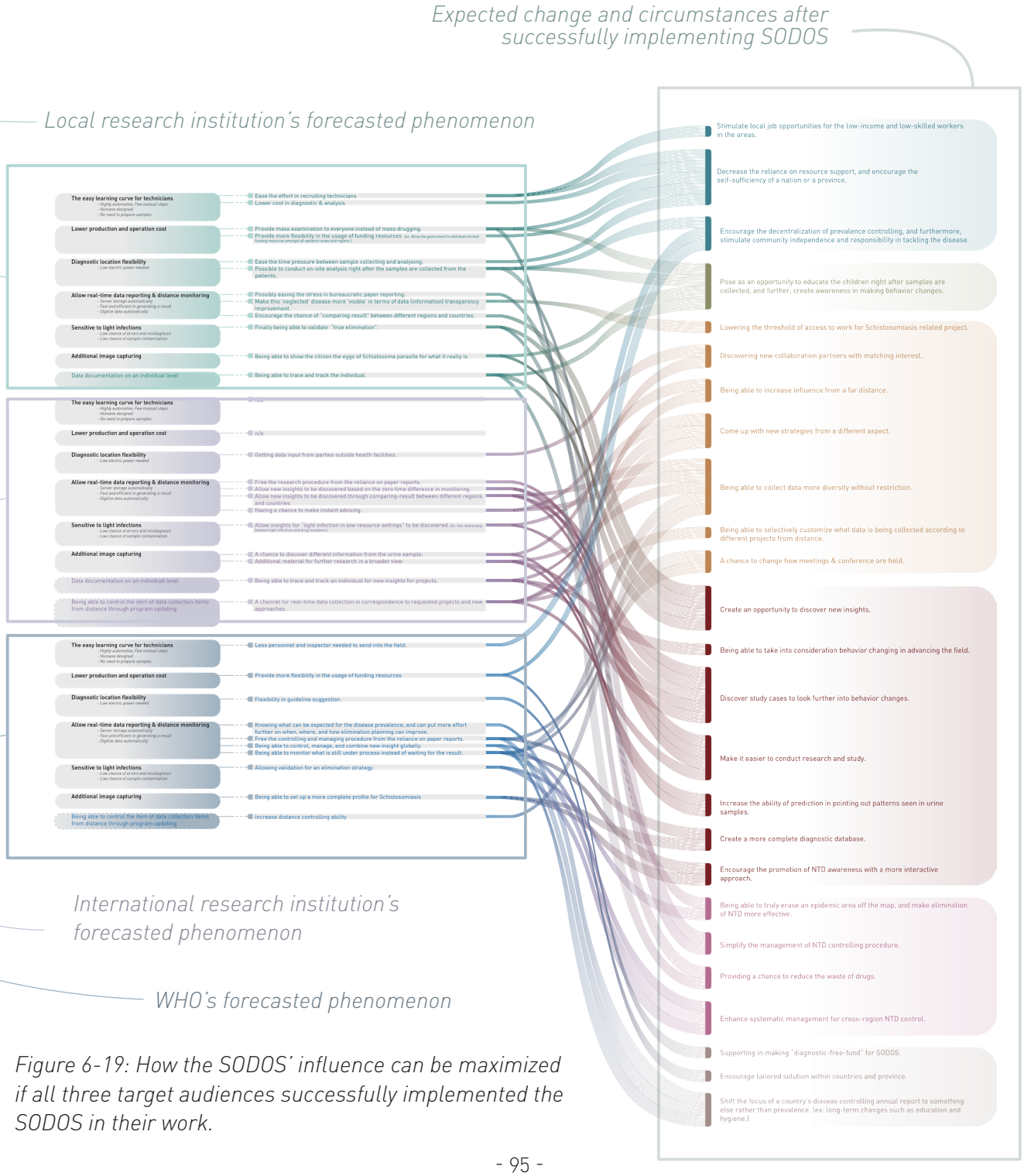
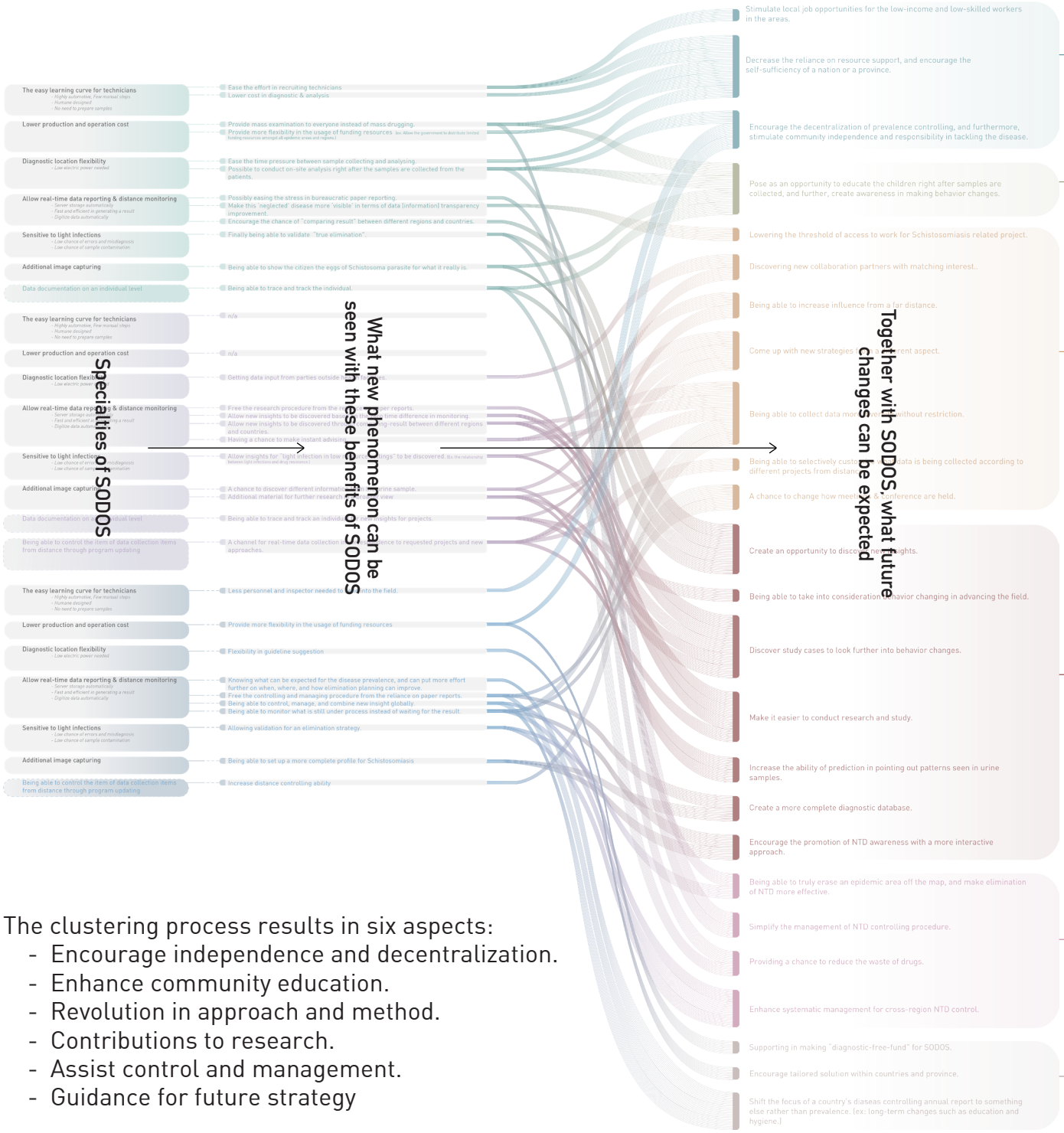

Expected change and circumstances after successfully implementing SODOS
Local research institution's forecasted phenomenon
The easy learning curve for technicians
- Highly automotive, Few manual steps
- Humane designed
- No need to prepare samples
Ease the effort in recruiting technicians
Lower cost in diagnostic & analysis
Lower production and operation cost
Provide mass examination to everyone instead of mass drugging.
Provide more flexibility in the usage of funding resources (ex: Allow the government to distribute limited funding resources amongst all epidemic areas and regions.)
Diagnostic location flexibility
- Low electric power needed
Ease the time pressure between sample collecting and analysing.
Possible to conduct on-site analysis right after the samples are collected from the patients.
Allow real-time data reporting & distance monitoring
- Server storage automatically
- Fast and efficient in generating a result
- Digitize data automatically
Possibly easing the stress in bureaucratic paper reporting.
Make this 'neglected' disease more 'visible' in terms of data (information) transparency improvement.
Encourage the chance of "comparing result" between different regions and countries.
Sensitive to light infections
- Low chance of errors and misdiagnosis
- Low chance of sample contamination
Finally being able to validate "true elimination".
Additional image capturing
Being able to show the citizen the eggs of Schistosoma parasite for what it really is.
Data documentation on an individual level
Being able to trace and track the individual.
The easy learning curve for technicians
- Highly automotive, Few manual steps
- Humane designed
- No need to prepare samples
n/a
Lower production and operation cost
n/a
Diagnostic location flexibility
- Low electric power needed
Getting data input from parties outside health facilities.
Allow real-time data reporting & distance monitoring
- Server storage automatically
- Fast and efficient in generating a result
- Digitize data automatically
Free the research procedure from the reliance on paper reports.
Allow new insights to be discovered based on the zero time difference in monitoring.
Allow new insights to be discovered through comparing-result between different regions and countries.
Having a chance to make instant advising.
Sensitive to light infections
- Low chance of errors and misdiagnosis
- Low chance of sample contamination
Allow insights for "light infection in low resource settings" to be discovered. (Ex: the relationship between light infections and drug resistance.)
Additional image capturing
A chance to discover different information from the urine sample.
Additional material for further research in a broader view
Data documentation on an individual level
Being able to trace and track an individual for new insights for projects.
Being able to control the item of data collection items from distance through program updating
A channel for real-time data collection in correspondence to requested projects and new approaches.
The easy learning curve for technicians
- Highly automotive, Few manual steps
- Humane designed
- No need to prepare samples
Less personnel and inspector needed to send into the field.
Lower production and operation cost
Provide more flexibility in the usage of funding resources
Diagnostic location flexibility
- Low electric power needed
Flexibility in guideline suggestion
Allow real-time data reporting & distance monitoring
- Server storage automatically
- Fast and efficient in generating a result
- Digitize data automatically
Knowing what can be expected for the disease prevalence, and can put more effort further on when, where, and how elimination planning can improve.
Free the controlling and managing procedure from the reliance on paper reports.
Being able to control, manage, and combine new insight globally.
Being able to monitor what is still under process instead of waiting for the result.
Sensitive to light infections
- Low chance of errors and misdiagnosis
- Low chance of sample contamination
Allowing validation for an elimination strategy.
Additional image capturing
Being able to set up a more complete profile for Schistosomiasis
Being able to control the item of data collection items from distance through program updating
Increase distance controlling ability
International research institution's forecasted phenomenon
WHO's forecasted phenomenon
Stimulate local job opportunities for the low-income and low-skilled workers in the areas.
Decrease the reliance on resource support, and encourage the self-sufficiency of a nation or a province.
Encourage the decentralization of prevalence controlling, and furthermore, stimulate community independence and responsibility in tackling the disease.
Pose as an opportunity to educate the children right after samples are collected, and further, create awareness in making behavior changes.
Lowering the threshold of access to work for Schistosomiasis related project.
Discovering new collaboration partners with matching interest..
Being able to increase influence from a far distance.
Come up with new strategies from a different aspect.
Being able to collect data more diversity without restriction.
Being able to selectively customize what data is being collected according to different projects from distance.
A chance to change how meetings & conference are held.
Create an opportunity to discover new insights.
Being able to take into consideration behavior changing in advancing the field.
Discover study cases to look further into behavior changes.
Make it easier to conduct research and study.
Increase the ability of prediction in pointing out patterns seen in urine samples.
Create a more complete diagnostic database.
Encourage the promotion of NTD awareness with a more interactive approach.
Being able to truly erase an epidemic area off the map, and make elimination of NTD more effective.
Simplify the management of NTD controlling procedure.
Providing a chance to reduce the waste of drugs.
Enhance systematic management for cross-region NTD control.
Supporting in making "diagnostic-free-fund" for SODOS.
Encourage tailored solution within countries and province.
Shift the focus of a country's diaseas controlling annual report to something else rather than prevalence. (ex: long-term changes such as education and hygiene.)

Figure 6-19: How the SODOS' influence can be maximized if all three target audiences successfully implemented the SODOS in their work.

Despite having a different vision and mission, common patterns can be seen from the new phenomenon created by SODOS (figures 6-14, 6-16, and 6-18) by categorizing similar ideas and connecting related topics, a shared understanding can be discovered.


Specialties of SODOS
What new phenomenon can be seen with these benefits of SODOS
Together with SODOS what future changes can be expected

The clustering process results in six aspects:

- Encourage independence and decentralization.
- Enhance community education.
- Revolution in approach and method.
- Contributions to research.
- Assist control and management.
- Guidance for future strategy

The six clustered results can be seen as change and new circumstances after the successful implementation of SODOS in the working procedures of the three hypothetical target audiences.

1. Encourage independence and decentralization.

2. Enhance community education.

3. Revolution in approach and method.

4. Contributions to research.

5. Assist control and management.

6. Guidance for future strategy.

(For a larger image see page 98)

** Guidance: For Practical Use >>*

[Clustering for deeper understanding]

When looking at the amount of conclusions, this step of clustering can be seen as simplifying the complexity. However, when looking at the weight and depth of the final clustering conclusion, this step is an important transition to build a shared understanding between the teams (Tassoul, 2007).

Some categorization can be obvious, while some may be debatable. The process of this activity triggers you to think of the meaning behind each listed phenomenon. This process can happen multiple times. In this exercise of SODOS, the clustering process happens two times: from 32 (12+10+10) to 25 and from 25 to 6.

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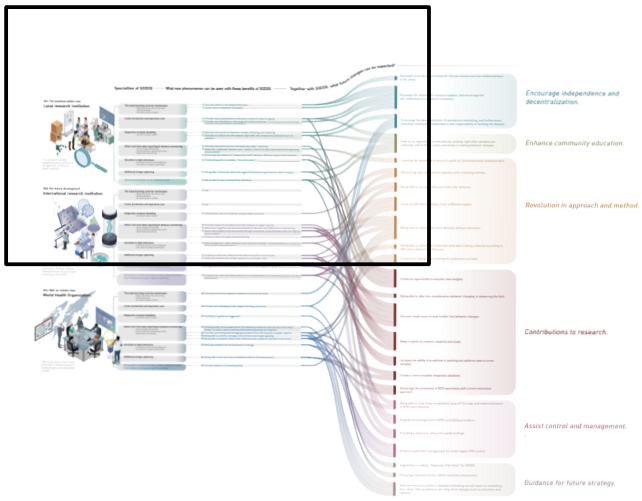


For the full image,
check the link:

http://tiny.cc/5eshbz

Specialties of SODOS ⟶ What new phenomenon can be se

TA1: For practical action now

Local research institution

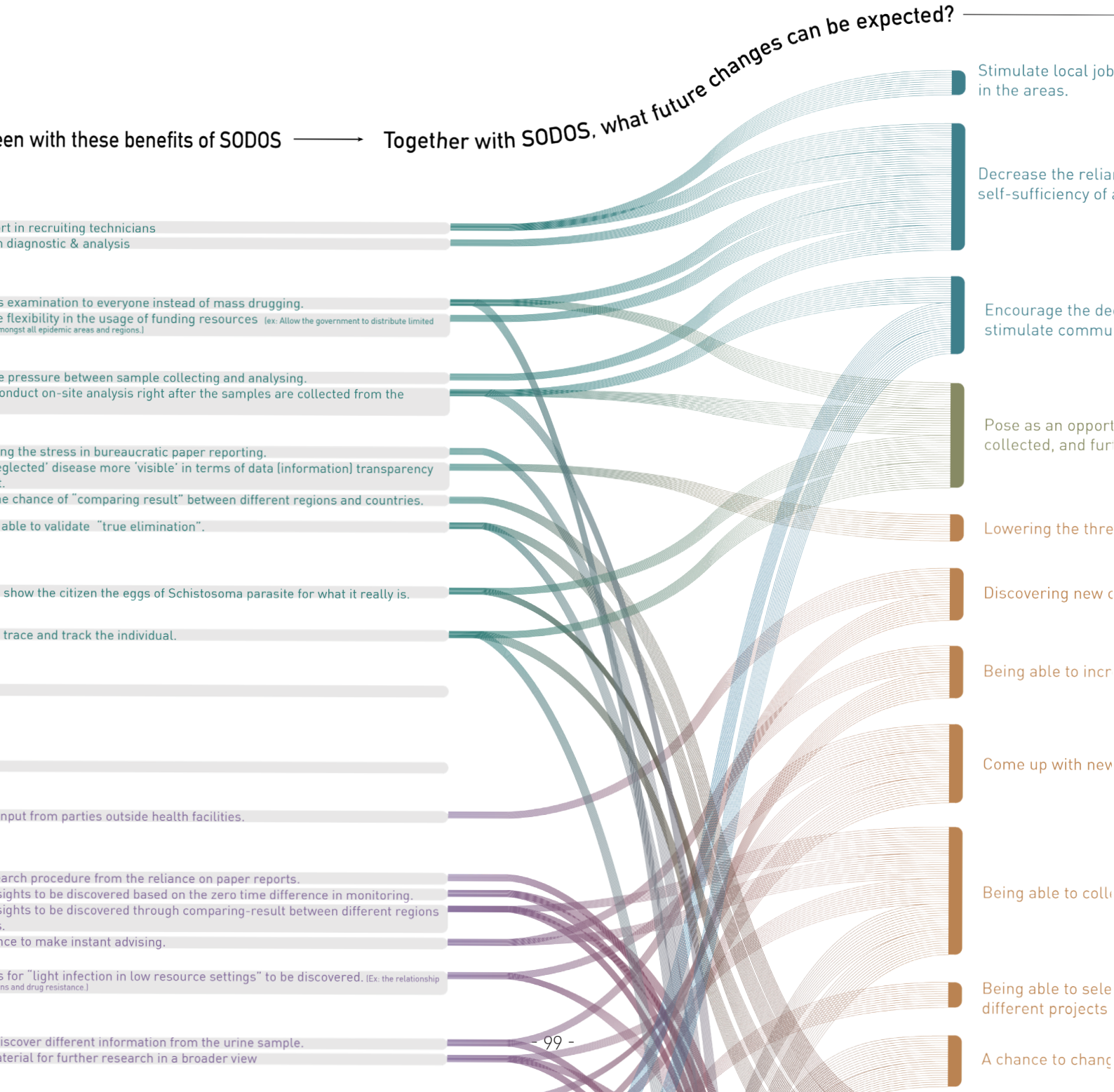
"It is all about carefully weighing the pros and cons of the approach, we have to make a decision."

- The easy learning curve for technicians
  - *Highly automotive, Few manual steps*
  - *Humane designed*
  - *No need to prepare samples*
- Lower production and operation cost
- Diagnostic location flexibility
  - *Low electric power needed*
- Allow real-time data reporting & distance monitoring
  - *Server storage automatically*
  - *Fast and efficient in generating a result*
  - *Digitize data automatically*
- Sensitive to light infections
  - *Low chance of errors and misdiagnosis*
  - *Low chance of sample contamination*
- Additional image capturing
- Data documentation on an individual level

TA2: For future development

International research institution

- The easy learning curve for technicians
  - *Highly automotive, Few manual steps*
  - *Humane designed*
  - *No need to prepare samples*
- Lower production and operation cost
- Diagnostic location flexibility
  - *Low electric power needed*
- Allow real-time data reporting & distance monitoring
  - *Server storage automatically*
  - *Fast and efficient in generating a result*
  - *Digitize data automatically*
- Sensitive to light infections
  - *Low chance of errors and misdiagnosis*
  - *Low chance of sample contamination*
- Additional image capturing


Together with SODOS, what future changes can be expected?
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in the areas.
Decrease the relia
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Encourage the de
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Lowering the thre
Discovering new
Being able to incr
Come up with new
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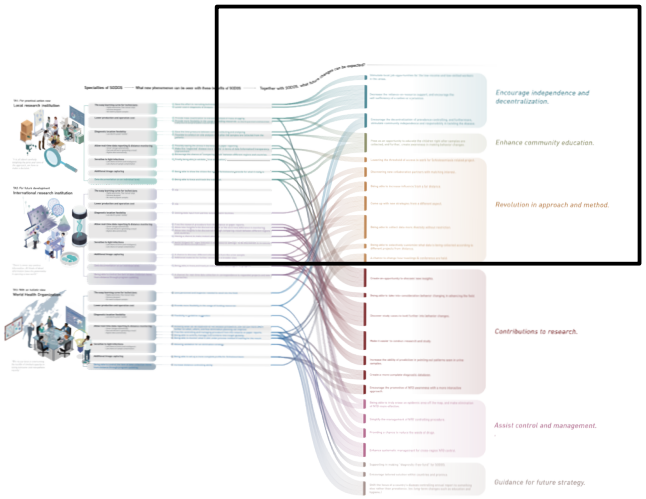

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Together with SODOS, what future changes can be expected?

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Encourage independence and decentralization.

Enhance community education.

Revolution in approach and method.

"There is never any useless information. All kinds of detail information have the potentiality in opening a new world."

Allow real-time data reporting & distance monitoring
- *Server storage automatically*
- *Fast and efficient in generating a result*
- *Digitize data automatically*

→ Free the res
→ Allow new in
→ Allow new in and countrie
→ Having a cha

Sensitive to light infections
- *Low chance of errors and misdiagnosis*
- *Low chance of sample contamination*

→ Allow insight between light infecti

Additional image capturing

→ A chance to
→ Additional m

Data documentation on an individual level

→ Being able to

Being able to control the item of data collection items from distance through program updating

→ A channel fo approaches.

TA3: With an holistic view

World Health Organization

"We try our best in overcoming the hurdle of limited capacity in loving everyone and everywhere equally."

The easy learning curve for technicians
- *Highly automotive, Few manual steps*
- *Humane designed*
- *No need to prepare samples*

→ Less person

Lower production and operation cost

→ Provide more

Diagnostic location flexibility
- *Low electric power needed*

→ Flexibility in

Allow real-time data reporting & distance monitoring
- *Server storage automatically*
- *Fast and efficient in generating a result*
- *Digitize data automatically*

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Sensitive to light infections
- *Low chance of errors and misdiagnosis*
- *Low chance of sample contamination*

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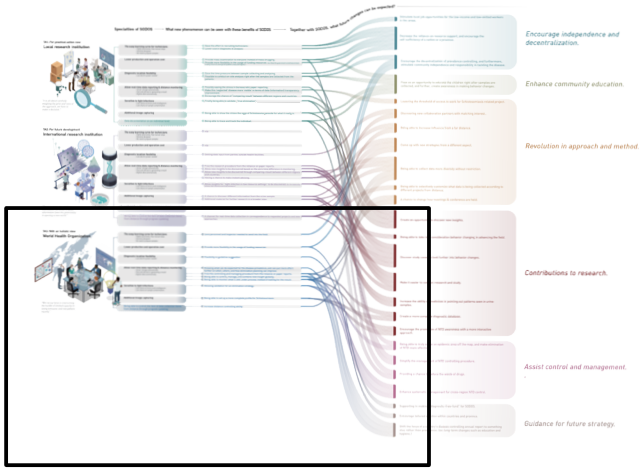

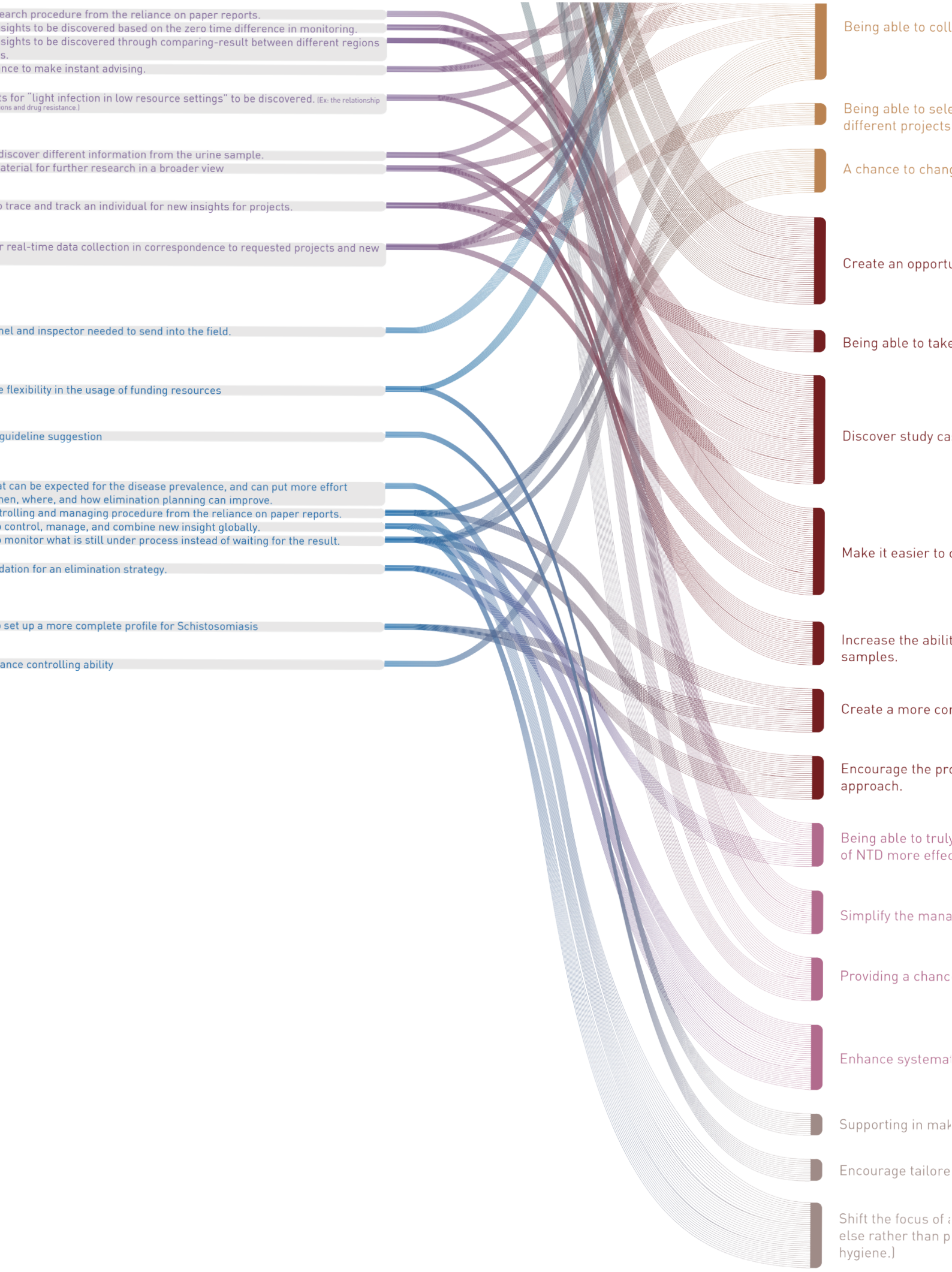
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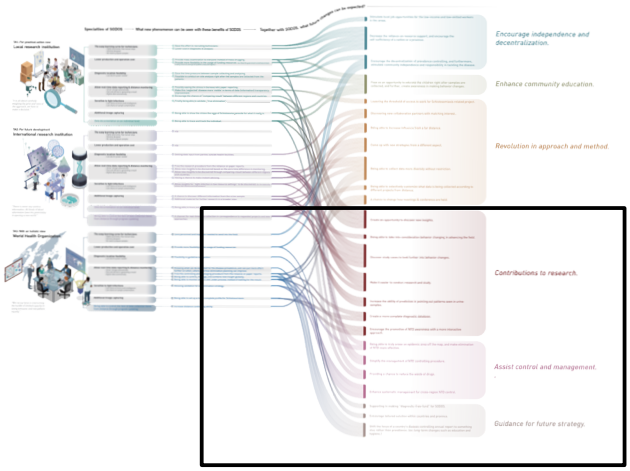

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Contributions to research.

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within countries and province.

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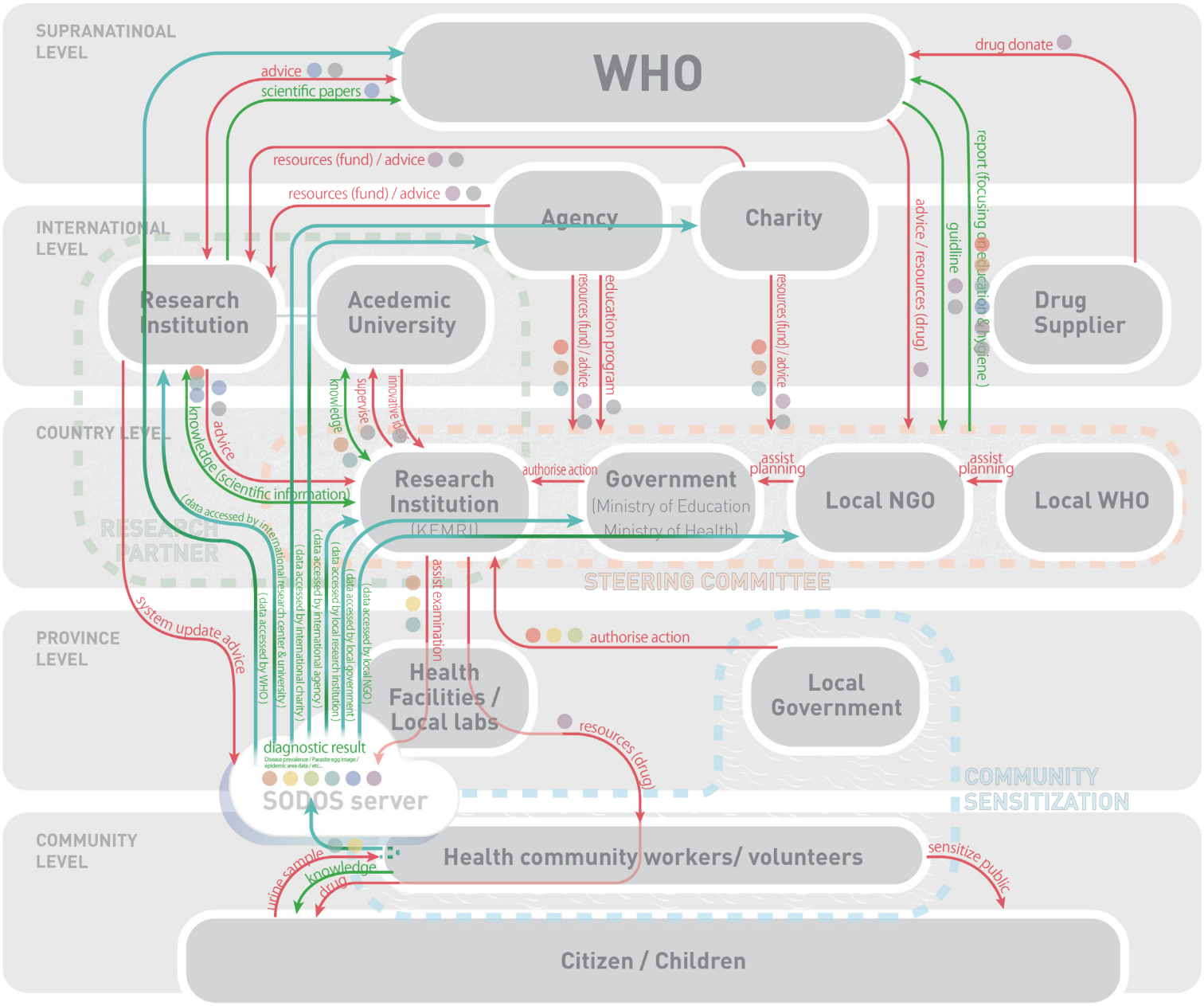
(ex: long-term changes such as education and

Guidance for future strategy.

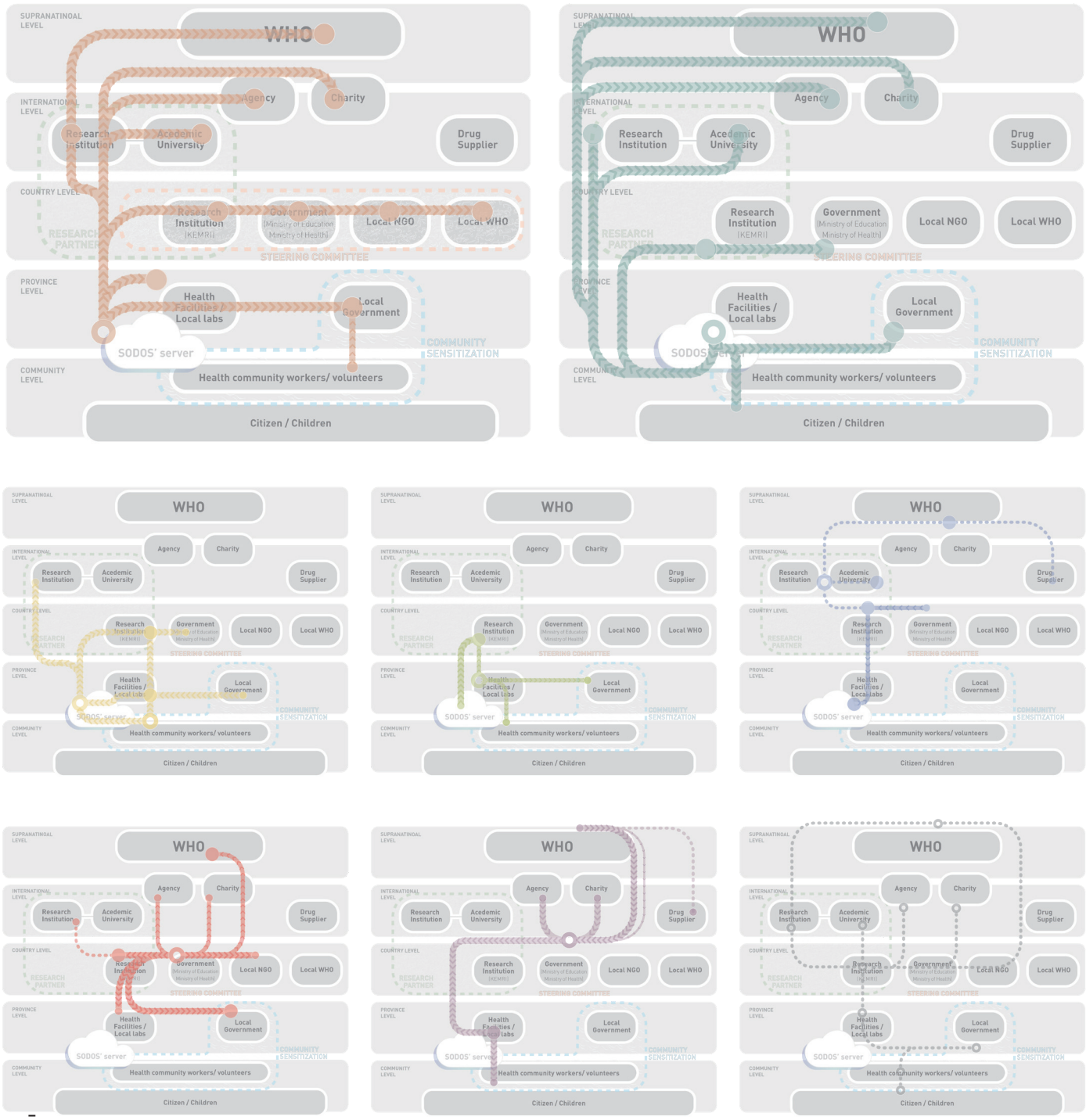
To further visualize the impact of SODOS, the data flow is put together onto the map discussed in chapter 6.2: *The flowing of data and information*. The ideal situation with the intervention of SODOS is illustrated in figures 6-20 and figures 6-21.



Figures 6-20: Data streams unified by SODOS. The requesting of data can be more direct compare to Chapter 5.1.

Data flowing direction (via SODOS)
Data / Information
Action

A. Country related data
B. Infected area related data
C. Citizen related data
D. Medical staff related data
E. Diagnostic related data
F. Parasite related data
G. Resources related data
H. (Other)



Figures 6-21: Speed of data streams unified by SODOS. The time spent to receive new data can be shorter compare to Chapter 5.2.

The source of data
Data as an important role
Data as a supportive role

Standardized data flow

Every 1 year or less
Every 2-5 years
Every 10 years

Non-Standardized data flow

(unscheduled)

6.5 Conclusion

Previously in this research, four gaps and drawbacks had been identified: 1) The directness of data flow. 2) The parallel and non-uniform of data. 3) Dead-ends in the data flow and 4) Restrictions of data flow due to bureaucracy and regulations. (See Chapter 5.3: *Gaps and drawback*).

By setting local research institutions, international research institutions and WHO as three hypothetical target audience, the intervention of SODOS, to a certain extent, has the potentiality to answer the four problem statements.

SODOS has a chance to unifiy diagnostic results related to the data needed in the elimination procedure of Schistosomiasis, which also helps reflect the data of the infected area.

With its low operation threshold, survey testing is a method that is easy to do across long distances, allowing people far from resources a chance to know more about Schistosomiasis. With the intervention of SODOS, instead of finding out just the disease prevalence, diagnostics can be closer to the citizen on an individual level, as samples can be processed on the spot, which creates the greatest chance to have children "see" the parasite eggs in their body. Currently, there is not better way of educating for awareness. Thereupon, drug waste that often happens after MDA can be eliminated when people know about making behavior change. For the controlling of the disease, SODOS' far distance monitoring and detailed data collection can better fulfill the diverse data requested from different stakeholders, which enhances the

** Guidance: For Practical Use >>*

[The optimized data footprint]

A blank relationship mapping sheet is provided in Appendix E. Try to put together all the information in the form of data (green lines) and actions (red lines).

With the help of the four gaps mentioned in chapter 5.3, review the new map created with the intervention of your innovation. What do you see? What can you be proud to share with others? What can still be improved in the future?

efficiency in data receiving, approach optimizing, situation monitoring, and research performing.

The hypothetical target audience can be directly influenced by SODOS. However, it is important to not forget the indirect beneficiaries, such as the government (both national and province), drug suppliers, and local community volunteers. Take the national government; for example; they authorize local research institutions and international organizations for humanitarian as well as developing actions. These governmental sectors are important key stakeholders to legitimate data storage and transfer. How can SODOS showcase its talents to these governmental stakeholders? Is it possible to turn this innovative diagnostic approach into a new standard?

"Being able to foresee the influence created by our intervention can help direct future development"

-- Mirte Vendel, Chief Operating Officer from AidX

Since SODOS is still in the early stages of development, these series of analysis help evaluate and prioritize the focus of development. With these foreseeable achievements (encourage independence and decentralization/enhance community education/revolution in approach and method/contributions to research/assist control and management/ guidance for future strategy), AidX has its blueprint to illustrate the vision for this innovation. This thinking approach lays the foundation for AidX to take strategic action and aim for long-term interventions that can better sustainability.

Reflection of this exercise with SODOS

The exercise of SODOS' strategic future planning, presented in this chapter, was carried out smoothly without too much resistance. Thanks to the correspondent of SODOS' lean and elite team, the discussion with AidX and SODOS' development team has always been conducted efficiently to the point; freedom is also allowed in presenting suggestions.

It is noteworthy to realize, for innovation, the interest of beneficiaries for a product or service is also possible to be complex, as the innovation may be part of a bigger project, or been funded by another party, which affects the autonomy sufficiency. Despite this foreseen hurdle of applying this series of analysis, this approach is advice to be conducted in the early stage of development to trigger out-of-the-box solution and minimize bias in the discussion of future planning.

7 Review & Conclusion -
The swim in the vibe of digital data

This is exploratory qualitative research, triggered by AidX's new creation - SODOS aimed at paving the way for future eHealth and mHealth interventions in the field of Schistosomiasis in low-resource settings. Through a series of responsibility positioning, data usage patterning, expert interviews, and information mapping, this research further proposed directions for future improvements through the lens of data, aiming to herald the future for people with aspirations of making changes.

Despite the same goal to fight neglected diseases, stakeholders each have their vision and mission in playing their roles. Understanding the motive behind their actions can help clarify innovation proposals of eHealth service and mHealth devices. Data can be multi-relational; however, the fundamental cause and effect of data can help filter out noise. By matching data with the disease combating procedure, it is then able to pattern the importance of data, creating a chance to prioritize the urgency of intervention.

Among all the neglected diseases, this analyzing approach was chosen to define Schistosomiasis Haematobium. For other complicated neglected disease or health-related issue that require concerted efforts of multiple parties, the researcher demonstrated the streamlining process with a holistic view.

The effectiveness of intervention can take years. The ultimate goal of the project is to encourage the creation of sustainable changes. It may take a while for this map to show effectiveness, as long-term strategy takes time.

The exercise of SODOS is presented in Chapter 6. Had it not been for the analysis from stakeholders to data (from chapter 3 to 5), the future developing direction for SODOS could be untenable. Because of the research, the developing direction of SODOS has a chance to become competitive. Understanding the market by following the systematic steps of the research can help innovation in standing the test of time.

There is a need to have these maps dynamically updated and refined regularly, on one hand, to meet the latest business solutions and collaborative arrangements of stakeholders, on the other hand, to keep up with the fast development of digital technology.

-

-

7.1 Mapping Validation

"Each of us has our own area and language of what we are good at. It is amazing how this research can be taking such a high-level view and by drawing in all different expertise from different areas."

-- Federica Giardina, Research Scientist from EMC

Validation of the research was conducted with a research scientist at Erasmus Medical Center and a researcher at African Studies Centre Leiden. Having SODOS presented in the previous chapter as an exercise of using this series of analysing approach, chief operating officer at AidX also participated in the validation phase. The method used in analyzing Schistosomiasis-related data was explained and discussed to see if it can be relevant to their work practically. The following are insights given from these interviewees.

Collaboration and partnership is now a trend in the field of science and academia. Researchers are encouraged to have partners from different expertises. Multidisciplinary angles are expected. However, the world is indeed missing the big picture. Finding the right remedy to the problem can be difficult when people that are familiar with digital technology and advance medical skills are often considered "outsiders" of the NTD epidemic content.

Such a map help each stakeholder seek potential partnership candidates. Validation interviewees were able to identify themselves on the map, reflect their work from a holistic view, interpret data collection problems they normally deal with in work through the map, and further realize what has to be optimized to ease the problem. Having a better understanding of what is happening from a bigger scope helps people think from a different perspective and even minimizes bias when taking a new approach.

The collection of qualitative data is mentioned by the validation interviewees once again. Information like behavior, personal reinfection history, and frustrations are likely to be left out. Such advice is also reflected in the development suggestion for SODOS in chapter 7.3. The practicability of such aspect will also be reminded in chapter 7.3: future recommendations.

"The feeling of ownership is very important. Only if you make them the owner of the problem that they will take the action that's needed to interrupt the transmission."

-- Sara Kleine Vennekate, Junior Researcher from African Studies Centre Leiden

Routine and systematic may be a way to ensure quality and familiarity; however, it is easy for people to overlook their original intentions or aspirations. This research helps remind stakeholders of their uniqueness and their role in the world. It is noteworthy to realize that this awareness in making changes is also applicable to local government and citizens in the epidemic areas.

7.2 Limitation

As aforementionedy, to keep the sets of data analysized relevant, the research requires regular updates and input. Technology will improve; stakeholders may also shift. Soon in 2020, WHO will be announcing the new roadmap.

Aside from the aspect of time, content is also a critical variability in the research. Low-resources setting countries can be relatively different in terms of development level. Take Chad, for example; health systems can be far from the situation in Kenya. Having still plenty of urgent issues to take care of, it is non-avoidable to make sure neglected disease

is on the priority list of "task to solve," otherwise, efforts and good intention can likely end in vain.

The research approach, to a certain extent, is still based on a (semi)developed WHO and government NTD planning. For countries that are not even in the picture of WHO MDA, is it possible to use the research approach? Are eHealth and mHealth able to work by having this strategic starting point even if no good infrastructure exists in the country and health system?

The basic architecture of the data mapping in this research is based on expert interviews with stakeholders. However, the aspect of WHO, local government, and the citizen is collected from literature reviews, seminars, or pass on by other interviewees. The number of interviews is advice to increased to enhance cross-reference and to correlate information.

Digital data intervention for health does not always start with the idea of "let's do something for eHealth." It often comes with a more bottom-up intention (ex: to help ill children), and end up choosing e-health as a solution (ex: "maybe we can do this via SMS"). The research, however, is designed for people that started their innovation consciously with "working with data." This fact, to a certain extent, restricted the influence of the research, as the guidance of the research may not follow the thinking flow of these bottom-up innovators, which makes the approach unrealistic.

Kenya, with its development, can be considered as an insufficient representation for low-resource setting countries. Schistosomiasis, despite being one of the deadliest neglected diseases, can also not represent all NTD. Thus, this study may not be generalizable as it was only done with one country and a small sample. To demystify digital data usage for NTS. More mapping sample from different countries and diseases is needed to draw credible conclusions.

7.3 For Future Researchers

The following are future recommendations for researchers who are interested in further exploring this project.

For people who further work on the data flow of NTD

As mentioned in the chapter 7.2, a limitation of the study was the number of interviews, further interviews will benefit the credibility of the research. To help put to the map to test, making the mapping of data interactive (ex: on a webpage) can increase regular update and makes it easier for people to contribute their experience in making the data map trustworthy.

Stakeholders in a non-standard data flow (see chapter 3.3.2) can be relevantly diverse in comparison to a standard data flow. In the research, the analysis focused mainly on international research institutions for the stakeholders within the non-standard. What about indirect stakeholders, like drug suppliers and universities?

Currently, eight categories of data are analyzed. The diversity and the detail of data can also be enriched to discover a new aspect. Is there a better way to categorize the needed data? Aside from capturing (dynamic data) and collecting (non-dynamic data), is there another way to further categorize qualitative data (ex: education, awareness, etc.)?

For people who further work on SODOS

The research is currently conducted based on the situation in Kenya. Especially in the early stage of development, AidX should conside other feasibility aspects, such as the market and partnership network. In chapter 6.3, features like individual data documenting and far distance systemupdating are expected from SODOS. These are only ideal features without taking into consideration the viability. How can SODOS acquire such a data collection ability? Are there other features that can trigger the interest of a potential target audience?

As mentioned in Chapter 6.1.2, making the average cost per SODOS' diagnostic under $1 is important to make SODOS competitive. What unnecessary data collection can be left out to shorten the diagnostic time and reduce the cost? How should SODOS position itself to compete with microscopy egg count?

For all people that wish to contribute to the elimination of NTD with (digital) data

The situation in low-resource setting countries can be different. It may be interesting to look into extreme cases in which WHO has not entered the area. Having such a view will help remove the bias of the project and help get the project down-to-earth. For these backward countries, it is also worthwhile for future researchers to study the possibility of bypassing the structure of government and policies while giving guidance to elimination intervention.

As mentioned in chapter 7.2, the current analysis approach of the research is more suitable for people who started their innovation from digital data. For designs that end up being eHealth innovations, a different entry point might be needed before then can try out the strategy guidance mentioned in this report.

The awarenessof both education and behavior changing in local people, health workers, governmental person has been repeatedly mentioned from interviewees. From Kenya (in comparison to all, well developed) to Chad (in comparison to all, poorly developed), this aspect of awareness is equally important. To ultimately end a neglected disease, everyone should take responsibility and become the problem owner of the issue. However, such an aspect is not yet the main focus in the WHO guidelines. This lack of focus could be relatively difficult to deal with especially when it comes to systematic control. These human-centered-mindset-changing ends up to be one of the most important missing puzzles, and one of the most difficult ones to resolve.

Combating disease requires a long-distance running mindest, perseverance, determination, and tolerance for frustration. One single individual with ambition cannot achieve the elimination of a disease; one party with a good idea can not eradicate the harm caused by disease. One creative approach can not suddenly create miracles. Combating disease is a relay race that requires not only the strengths of different experts from all aspects but also the right strategy and the right knowledge.

Abbreviations

BoP	Base of Pyramid
CAA	Circulating Anodic Antigen
CCA	Circulating Cathodic Antigen
CIFF	Children Investment Fund Foundation
CWW	Children Without Worms
DHIS	District Health Information System
eHealth	Electronic Health
EMR	Electronic Medical Record
EMC	Erasmus Medical Center
FOI	Force Of Infection
GDPR	General Data Protection Regulation
HIS	Healthcare Information Systems
IATI	International Aid Transparency Initiative
IOM	International Organization of Migrants
IoT	Internet of Things
JICA	Japan International Cooperation Agency
KEMRI	Kenya Medical Research Institute
LRS	Low-resource Settings
LUMC	Leiden University Medical Center
MDA	Mass Drug Administration
ME	Mass Examination
mHealth	Mobile Health
MSF	Doctors Without Borders
MU	Mahidol University
NGO	Non-governmental Organizations
NMIMR	Noguchi Memorial Institute for Medical Research
NSBDP	National School-based Deworming Programme
UNICEF	The United Nations Children's Fund
USAID	U.S. Agency For International Development
PCR	Polymerase Chain Reaction
POC	Point of care
RDT	Rapid Diagnostic Testing
SCI	Schistosomiasis Control Initiative
SODOS	Smart Optical Diagnostic Of Schistosomiasis
STH	Soil-transmitted Helminths
VPN	Virtual Private Network
WHO	World Health Organization
YEP	Young Expert Program

Reference

Ackoff, R. L. (1989). *From data to wisdom. Journal of applied systems analysis*, 16(1), 3-9.

Africa Data Revolution Report (2016)

Africa Data Revolution Report (2018) http://webfoundation.org/docs/2018/10/African-data-revolution-report-brochure-publish.pdf

Akvo, *Design data-driven programmes that deliver results effectively, A step-by-step guide for programme managers in international development*, Retrieved on 10-07-2019 from: https://cdn2.hubspot.net/hubfs/1891949/Akvo%20eBook%20-%20Design%20data-driven%20development%20programmes%20that%20deliver%20results%20effectively.pdf

Ali, E. E., Chew, L., & Yap, K. Y. L. (2016). *Evolution and current status of mhealth research: a systematic review*. BMJ Innovations, 2(1), 33-40.

Alsallaq, R. A., Gurarie, D., Mbah, M. N., Galvani, A., & King, C. (2017). *Quantitative assessment of the impact of partially protective anti-schistosomiasis vaccines. PLoS neglected tropical diseases,* 11(4), e0005544.

Amoah, A.S. (2018). *Meetings at LUMC* on the 15th of February and the 15th of March, 2018.

Barbabella, F., Melchiorre, M. G., Quattrini, S., Papa, R., & Lamura, G. (2017). *How can eHealth improve care for people with multimorbidity in Europe?*. World Health Organization, Regional Office for Europe.

Barzilai-Nahon, K. (2006) *Gaps and Bits: Conceptualizing Measurements for Digital Divide/s*. The Information Society, 22, 5, 269-278.

Bonds, M. H., Dobson, A. P., & Keenan, D. C. (2012). *Disease ecology, biodiversity, and the latitudinal gradient in income.* PLoS biology, 10(12), e1001456.

Brindley, P. J. (1994). *Drug resistance to schistosomicides and other anthelmintics of medical significance.* Acta Tropica, 56(2-3), 213-231.

Bustinduy, A. L. & King, C. H. (2014). Chapter 53 – Schistosomiasis. In J. Farrar, P. J. Hotez, T. Junghanss, G. Kang, D. Lalloo & N. J. White (Eds), *Manson's Tropical Infectious Diseases* (Twenty-third Edition) (pp. 698- 725). Londen: W. B. Saunders.

Byrne, M. (2001). *Interviewing as a data collection method.* AORN journal, 74(2), 233-233.

Cullen, R. (2001) *Addressing the Digital Divide*. Online Information Review, 25, 5, 311–320.

Consulting, V. W. (2009). *mHealth for development: the opportunity of mobile technology for healthcare in the developing world.* Washington Dc and Berkshire, UK.

Daily Nation (2017). *Safaricom sacks 52 employees over M-Pesa.* Retrieved on 22-07-2019 from https://businesstoday.co.ke/safaricom-sacks-52-employees-m-pesa-fraud/

Data Zetu (2018) *Connecting Flows and Places*

De Montjoye, Y. A., Shmueli, E., Wang, S. S., & Pentland, A. S. (2014). *Open: Protecting the privacy of metadata through safe answers.* PloS one, 9(7), e98790.

Debra L. Dickson, IBT Global (2017) D*igital Health for Systems: Strengthening Family Planning Systems Through Time and Resource efficiency.* Photo credit: ©2015 Ueli Litscher, Courtesy of Photoshare. Retrieved on 22-07-2019 from http://www.comminit.com/edutain-africa/content/digital-health-systems-strengthening-family-planning-systems-through-time-and-resource-e

Deelder, A. M., Miller, R. L., Jonge, N. D., & Krijger, F. W. (1990). *Detection of schistosome antigen in mummies*. Lancet (British edition), 335(8691), 724-725.

Demchenko, Y., De Laat, C., & Membrey, P. (2014, May). *Defining architecture components of the Big Data Ecosystem.* In 2014 International Conference on Collaboration Technologies and Systems (CTS) (pp. 104-112). IEEE.

Donohue, R., Mashoto, K., Mubyazi, G., Madon, S., Malecela, M., & Michael, E. (2017). *Biosocial determinants of persistent schistosomiasis among schoolchildren in Tanzania despite repeated treatment*. Tropical medicine and infectious disease, 2(4), 61.

ESPEN, *Expended spacial project for elimination of neglected tropical disease, Schistosomiasis.* Retrieved on 11-06-2019 from http://espen.afro.who.int/diseases/schistosomiasis

Etzo, S., & Collender, G. (2010). *The mobile phone 'revolution' in Africa: rhetoric or reality?*. African affairs, 109(437), 659-668.

Fallah, M. P., Skrip, L. A., Raftery, P., Kullie, M., Borbor, W., Laney, A. S., ... & Coulter, S. (2017). *Bolstering community cooperation in Ebola resurgence protocols: combining field blood draw and point-of-care diagnosis.* PLoS medicine, 14(1), e1002227.

Farrell, S. H., Truscott, J. E., & Anderson, R. M. (2017). T*he importance of patient compliance in repeated rounds of mass drug administration (MDA) for the elimination of intestinal helminth transmission.* Parasites & Vectors, 10(1), 291.

FIND, n*eglected tropical disease* (2019),https://www.finddx.org/ntd/

Frost, S. (2015). *Drowning in big data? reducing information technology complexities and costs for healthcare organizations.*

Getoor, L. (2003). *Link mining: a new data mining challenge*. ACM SIGKDD Explorations Newsletter, 5(1), 84-89.

Gryseels, B., Polman, K., Clerinx, J., & Kestens, L. (2006). *Human schistosomiasis*. The Lancet, 368 (9541), pp. 1106-1118.

Gryseels, B., Strickland, G. T. (2013). Chapter 122 - Schistosomiasis. In A. J. Magill, E. T. Ryan, D. Hill & T. Solomon (Eds.), *Hunter's Tropical Medicine and Emerging Infectious Diseases* (Ninth Edition) (pp. 868- 883). London: W.B. Sauders.

Hey, J., Linsey, J., Agogino, A. M., & Wood, K. L. (2008). *Analogies and metaphors in creative design.* International Journal of Engineering Education, 24(2), 283.

HIS Policy – Role of National, *Regional and Global Levels in Building and Promoting HIS in Countries* https://www.mn.uio.no/ifi/english/research/networks/hisp/integrated-health-information-architecture/ch-11.pdf

Haque, F., Ball, R. L., Khatun, S., Ahmed, M., Kache, S., Chisti, M. J., ... & Sarnquist, C. (2017). *Evaluation of a smartphone decision-support tool for diarrheal disease management in a resource-limited setting.* PLoS neglected tropical diseases, 11(1), e0005290.

Hoffman, D.L. and Novak, T.P. (1998) *Bridging the Racial Divide on the Internet.* Science, 280, 5362, 390-391.

Hotez, P. J., Molyneux, D. H., Fenwick, A., Ottesen, E., Sachs, S. E., & Sachs, J. D. (2006). *Incorporating a rapid-impact package for neglected tropical diseases with programs for HIV/AIDS, tuberculosis, and malaria.* PLoS medicine, 3(5), e102.

Inobaya, M. T., Olveda, R. M., Chau, T. N., Olveda, D. U., & Ross, A. G. (2014). *Prevention and control of schistosomiasis: a current perspective*. Research and reports in tropical medicine, 2014(5), 65.

Jagun, A., & Heeks, R. (2007). *Mobile phones and development: the future in new hands?*. Insights/id21 (Programme), (69).

Kardia Mobile. Retrieved on 25-07-2019 from https://www.youtube.com/watch?time_continue=42&v=r6RWolM6mjg

Kallestrup, P., Zinyama, R., Gomo, E., Butterworth, A. E., van Dam, G. J., Gerstoft, J., ... & Ullum, H. (2006). *Schistosomiasis and HIV in rural Zimbabwe: efficacy of treatment of schistosomiasis in individuals with HIV coinfection.* Clinical infectious diseases, 42(12), 1781-1789.

Krentel, A., Fischer, P. U., & Weil, G. J. (2013). *A review of factors that influence individual compliance with mass drug administration for elimination of lymphatic filariasis.* PLoS neglected tropical diseases, 7(11), e2447.

Khoury, M. J., & Ioannidis, J. P. (2014). *Big data meets public health.* Science, 346(6213), 1054-1055.

King, C. H. (2009). *Toward the elimination of schistosomiasis.* New England Journal of Medicine, 360(2), 106-109.

King, C. H. (2010). *Parasites and poverty: the case of schistosomiasis.* Acta Tropica, 113(2), 95-104.

Le, L., & Hsieh, M. H. (2017). *Diagnosing urogenital schistosomiasis: dealing with diminishing returns*. Trends in Parasitology, 33(5), 378-387. Retrieved on 12-04-2019 though Lisette van Lieshout from LUMC

LSTM. *The Disease Data Management System (DDMS),* Retrieved on 05-08-2019 from https://www.lstmed.ac.uk/research/departments/vector-biology/monitoring-and-evaluation/the-disease-data-management-system

Leuthesser, L. and Kohli, C. (1997), *"Corporate identity: the role of mission statements"*, Business Horizons, Vol. 40, pp. 59- 66.

Marsh, D. (2018). *How digital transformation is shaping industries* Retrieved on 22-07-2019 from https://www.cio.com/article/3305780/how-digital-transformation-is-shaping-industries.html

Medscape*: Schistosomiasis (Bilharzia)* Retrieved on 10-06-2019 from https://emedicine.medscape.com/article/228392-overview

Mehl, G., & Labrique, A. (2014). *Prioritizing integrated mHealth strategies for universal health coverage.* Science, 345(6202), 1284-1287.

Mehta, N., & Pandit, A. (2018). *Concurrence of big data analytics and healthcare: A systematic review.* International journal of medical informatics, 114, 57-65.

mHealth Alliance Retrieved on 25-07-2019 from https://mhealthknowledge.org/

National Institutes of Health, BD2K (2014); bd2k.nih.gov/index.html#sthash.0uOeCsq3.dpbs.

Nour N. M. (2010). *Schistosomiasis: health effects on women.* Reviews in Obstetrics & Gynecology, 3(1), 28–32.

Oluwasogo, O. A. & Fagbemi, O. B. (2013). *Prevalence and risk factors of Schistosoma haematobium infections among primary school children in Igbokuta Village, Ikorodu North Local Government, Lagos State*. IOSR Journal of Nursing and Health Science (IOSR-JNHS). e-ISSN: 2320–1959.p- ISSN: 2320–1940 Volume 2, Issue 6 (Nov. – Dec. 2013), PP 62-68 www.iosrjournals.org.

PATH, Retrieved on 05-08-2019 from https://www.path.org/

Pediatric praziquantel consortium: schistosomiasis Treating preschool children. Retrieved on 11-06-2019 from https://www.pediatricpraziquantelconsortium.org/sites/schisto/files/0718PZQ_Flyer%20EN-KGaA_A5.pdf

Perkel, J. M. (2017). Pocket laboratories.

Prahalad, C. K. (2009). *The fortune at the bottom of the pyramid, revised and updated 5th anniversary edition: Eradicating poverty through profits.* FT Press.

Pruitt, J., & Adlin, T. (2010). *The persona lifecycle: keeping people in mind throughout product design.* Elsevier.

Polderman, A. M. (2005). *Medische parasitologie* (4th completely revised edition). Arnhem: Uitgeverij Syntax.

Public Health Agency of Canada. P*an Canadian Public Health Network: Guidelines for MPH programs in Canada*. Revived on 20,05,2019, from https://www.canada.ca/en/public-health/services/public-health-practice.html

PubMed (1998) *Drugs for parasitic infections.* Med Lett Drugs Ther. 40:1–12. Retrieved on 11-06-2019 from https://www.ncbi.nlm.nih.gov/pubmed?cmd=Retrieve&db=PubMed&list_uids=9442765&dopt=Abstract

Purkayastha, S., & Braa, J. (2013). *Big data analytics for developing countries–using the cloud for operational BI IN health.* The Electronic Journal of Information Systems in Developing Countries, 59(1), 1-17.

Qelp. (2019), *Africa smartphone penetration at tipping point.* Retrieved on 21-07-2019 from https://www.qelp.com/insights/africa-smartphone-penetration-at-tipping-point/

Roozenburg, N. F., & Eekels, J. (1995). *Product design: fundamentals and methods* (Vol. 2). John Wiley & Sons Inc.

Ross Ag, B. P., Sleigh, A. C., Olds, G. R., & Li, Y. (2002). Williams GM, McManus DP. *Schistosomiasis. N* En2f f Med, 346, 1212-1220.

Raghupathi, W. (2010). *Data mining in health care.* Healthcare Informatics: Improving Efficiency and Productivity, 211, 223.

Raghupathi, W., & Raghupathi, V. (2014). *Big data analytics in healthcare: promise and potential.* Health information science and systems, 2(1), 3.

Rahman, I.U., (2015) *Chapter 6 Data collection methods,* Lecture Notes on Statistics, pp.52.

Reach for change. *Didier brings mobile health to rural children in Chad.* Retrieved on 05-08-2019, from http://africa.reachforchange.org/en/impact/impact-social-entrepreneurs/didier-brings-mobile-health-rural-children-chad

Schistosomiasis fact sheets, WHO Retrieved on 05-08-2019, from https://www.afro.who.int/health-topics/schistosomiasis-bilharzia

Shi, L. (2012). *The impact of primary care: a focused review.* Scientific

Shuford, K. V., Turner, H. C., & Anderson, R. M. (2016). *Compliance with anthelmintic treatment in the neglected tropical diseases control programs: a systematic review.* Parasites & Vectors, 9(1), 29.

Sinkovics, Noemi. (2018). *Pattern matching in qualitative analysis.*

Tassoul, M. (2005). *Creative facilitation: a Delft approach*. VSSD.

Tassoul, M., & Buijs, J. (2007). *Clustering: An essential step from diverging to converging.* Creativity and Innovation Management, 16(1), 16-26.

Toor, J., Alsallaq, R., Truscott, J. E., Turner, H. C., Werkman, M., Gurarie, D., ... & Anderson, R. M. (2018). *Are we on our way to achieving the 2020 goals for schistosomiasis morbidity control using current World Health Organization guidelines?.* Clinical Infectious Diseases, 66(suppl_4), S245-S252.

Toor, J., Turner, H. C., Truscott, J. E., Werkman, M., Phillips, A. E., Alsallaq, R., ... & Anderson, R. M. (2018). T*he design of schistosomiasis monitoring and evaluation programs: The importance of collecting adult data to inform treatment strategies for Schistosoma Mansoni.* PLoS neglected tropical diseases, 12(10), e0006717.

Ugbomoiko, U. S., Dalumo, V., Ariza, L., Bezerra, F. S. M., & Heukelbach, J. (2009). *A simple approach improving the performance of urine reagent strips for rapid diagnosis of urinary schistosomiasis in Nigerian schoolchildren*. Memórias do Instituto Oswaldo Cruz, 104(3), 456-461.

Utzinger, J., Becker, S. L., van Lieshout, L., van Dam, G. J., & Knopp, S. (2015). *New diagnostic tools in schistosomiasis.* Clinical microbiology and infection, 21(6), 529-542.

Van Boeijen, A., Daalhuizen, J., van der Schoor, R., & Zijlstra, J. (2014). *Delft design guide: Design strategies and methods.*

van der Vorst, R. (2017). *Contrarian Branding: Stand out by camouflaging the competition*. BIS Publishers.

Vanderelst (2017) *The Importance of Vision and Mission Statements,* Retrieved on 09-07-2019, from https://www.linkedin.com/pulse/importance-vision-mission-statements-norja-vanderelst/

Vendel (2018) *The EC: a device to diagnose urinary schistosomiasis in Ghana: Designed for local facilities as well as large*-scale

community screening sessions

Walz, Y., Wegmann, M., Dech, S., Raso, G., & Utzinger, J. (2015). *Risk profiling of schistosomiasis using remote sensing: approaches, challenges and outlook*. Parasites & vectors, 8(1), 163.

Wei, K.-K., Teo, H.-H., Chan, H.C. and Tan, B.C.Y. (2011) *Conceptualizing and Testing a Social Cognitive Model of the Digital Divide.* Information Systems Research, 22, 1, 170-187.

Webster, J. P., Molyneux, D. H., Hotez, P. J., & Fenwick, A. (2014). *The contribution of mass drug administration to global health: past, present, and future.* Philosophical Transactions of the Royal Society B: Biological Sciences, 369(1645), 20130434.

White, F. (2015). *Primary health care and public health: foundations of universal health systems.* Medical Principles and Practice, 24(2), 103-116.

Wood, C. S., Thomas, M. R., Budd, J., Mashamba-Thompson, T. P., Herbst, K., Pillay, D., ... & Stevens, M. M. (2019). *Taking connected mobile-health diagnostics of infectious diseases to the field.* Nature, 566(7745), 467.

World Health Organization. (2000). *The world health report 2000: health systems: improving performance.* World Health Organization.

World Health Organization. (2011). A*ccelerating work to overcome the global impact of neglected tropical diseases. A roadmap For Implementation*

World Health Organization. (2011). *Helminth control in school-age children: a guide for managers of control programs.* Geneva: World Health Organization.

World Health Organization. (2006). *Preventive chemotherapy in human helminthiasis. Coordinated use of anthelmintic drugs in control interventions: a manual for health professionals and program managers.* World Health Organization.

World Health Organization. (2013). *Schistosomiasis: progress report 2001-2011, strategic plan 2012-2020.* Retrieved on 10-06-2019 from https://www.who.int/neglected_diseases/news/NTD-Roadmap-targets-2021-2030.pdf?ua=1

World Health Organization. (2015) *The MAPS toolkit: mHealth assessment and planning for scale.* Retrieved on 22-07-2019 from https://apps.who.int/iris/bitstream/handle/10665/185238/9789241509510_eng.pdf?sequence=1

World Health Organization. (2015) *Schistosomiasis Data Platform Stakeholder Meeting report*, 3 – 4 September 2015, Retrieved on 09-07-2019 from https://www.who.int/tdr/news/2015/report-schisto-meeting-3-4Sept2015.pdf

Your Genome (n.d.). *What is schistosomiasis?* Retrieved on 10-08-2018, from https://www. yourgenome.org/facts/what-is-schistosomiasis.

Appendix

A. Tool kits - stakeholders/data companies

B. Risk factors' and 'remoting sensing data' for Schistosomiasis transmission

C. Interview guide/interview notes (Comparison table between MDA and ME)

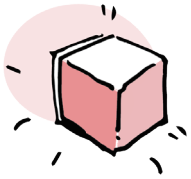
D. The iteration of data flowing maps

E. Blank mapping sheet

A. Tool kits - stakeholders/data companies

A.a. Tool kits for stakeholders

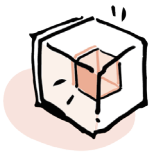
A Country (national) related data



Country related data (national data)

a. Population
b. Gender ratio
c. GDP
d. Land surface size
e. Occupation rate
f. Fertility rate
g. Mortality rate
h. Migration rate
i. Literacy rate
j. Exploitation rate

B Infected area (regional) related data



Infected area related data (regional / state data)

a. Infected area location
b. Infected area weather condition
c. Infected area population
d. Location of health-related facilities
e. Average accessibility of health facilities (per population)

C Citizen / Patient related data

Citizen / Patient-related data

a. Inhabitants location of patients
b. Age of patient
c. Frequency in health check
d. Occupation of patient
e. Salary/ income of the patient
f. The contact information of the patient
g. Travel history of patients
h. Diet of patients
i. Adherence

D Medical staff related data

Medical staff related data

a. Number of medical staff
b. Gender of medical staff
c. Workload of medical staff (per hour)
d. Position of medical staff

E Diagnostic result related data

Diagnostic result related data

a. Urine samples
b. Location of diagnostic providing location
c. Level of diagnostic providing facilities
b. Date and time of diagnostic
e. Amount of urine (per day)
f. Appearance of urine
g. Specific gravity (hydration / kidney illness)
h. Glucose of urine (Diabetes / kidney illness)
i. Protein of urine (High blood pressure / kidney illness)
j. Bilirubin (liver illness)
k. PH (acid) of urine
l. Nitrite of urine (infection)
m. Color of urine
n. Occult blood of urine (urinary system problem / Rhabdomyolysis)
o. Red blood cell / HPF
p. White blood / HPF
q. Epithelial cell / HPF
r. Casts / LPF
s. HCG of urine (Pregnancy)
t. Urine cytology (Cancer)
u. Yeast / Fungus / Parasite (schistosomiasis eggs)

F Parasite related data

Parasite related data

a. Parasite prevalence
b. Parasite taxon
c. Parasite size
d. Parasite-host species
e. Parasite intensity
f. Parasite antigens (CAA, CCA)
g. Locality

G Resources related data

Resources related data

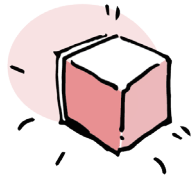
a. Drug coverage (per area)
b. Budget (per project)
c. Medical equipment and device providing situation (per area)
d. Expert (per area)

H Other (qualitative) data

Other (qualitative) data

a. Frustrations
b. Improvement advice
c. Living environment situation
d. Working environment situation

A Country (national) related data



- ○ Dynamic Data (measure / capture)
- ○ Static Data (request / collect)

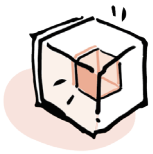
○ as INPUT

- ▸ Source of input-data:
  - ○ Primary Data, from _____
  - ○ Secondary Data, from _____
- ▸ Accuracy of input-data requirement:
  - ○ <50% ○ 50-75%
  - ○ 75-90% ○ >90%
- ▸ Frequency of (input-data) updates:
  - ○ Every time when changed
  - ○ Once a month
  - ○ Once a season
  - ○ Once a year
  - ○ Once every three years or more
  - ○ Other: _____

○ as OUTPUT

- ▸ Format of data:
  - ○ Report ○ Data base
  - ○ other: _____
- ▸ Data output frequency::
  - ○ Every time when changed
  - ○ Once a month
  - ○ Once a season
  - ○ Once a year
  - ○ Once every three years or more
  - ○ Other: _____

B Infected area (regional) related data



- ○ Dynamic Data (measure / capture)
- ○ Static Data (request / collect)

○ as INPUT

- ▸ Source of input-data:
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  - ○ Once a year
  - ○ Once every three years or more
  - ○ Other: _____

○ as OUTPUT

- ▸ Format of data:
  - ○ Report ○ Data base
  - ○ other: _____
- ▸ Data output frequency::
  - ○ Every time when changed
  - ○ Once a month
  - ○ Once a season
  - ○ Once a year
  - ○ Once every three years or more
  - ○ Other: _____

C Citizen / Patient related data

- ○ Dynamic Data (measure / capture)
- ○ Static Data (request / collect)

○ as INPUT

- ▸ Source of input-data:
  - ○ Primary Data, from _____
  - ○ Secondary Data, from _____
- ▸ Accuracy of input-data requirement:
  - ○ <50% ○ 50-75%
  - ○ 75-90% ○ >90%
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○ as OUTPUT

- ▸ Format of data:
  - ○ Report ○ Data base
  - ○ other: _____
- ▸ Data output frequency::
  - ○ Every time when changed
  - ○ Once a month
  - ○ Once a season
  - ○ Once a year
  - ○ Once every three years or more
  - ○ Other: _____

D Medical staff related data

- ○ Dynamic Data (measure / capture)
- ○ Static Data (request / collect)

○ as INPUT

- ▸ Source of input-data:
  - ○ Primary Data, from _____
  - ○ Secondary Data, from _____
- ▸ Accuracy of input-data requirement:
  - ○ <50% ○ 50-75%
  - ○ 75-90% ○ >90%
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○ as OUTPUT

- ▸ Format of data:
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  - ○ other: _____
- ▸ Data output frequency::
  - ○ Every time when changed
  - ○ Once a month
  - ○ Once a season
  - ○ Once a year
  - ○ Once every three years or more
  - ○ Other: _____

E Diagnostic result related data

- ○ Dynamic Data (measure / capture)
- ○ Static Data (request / collect)

○ as INPUT

- ▸ Source of input-data:
  - ○ Primary Data, from _____
  - ○ Secondary Data, from _____
- ▸ Accuracy of input-data requirement:
  - ○ <50% ○ 50-75%
  - ○ 75-90% ○ >90%
- ▸ Frequency of (input-data) updates:
  - ○ Every time when changed
  - ○ Once a month
  - ○ Once a season
  - ○ Once a year
  - ○ Once every three years or more
  - ○ Other: _____

○ as OUTPUT

- ▸ Format of data:
  - ○ Report ○ Data base
  - ○ other: _____
- ▸ Data output frequency::
  - ○ Every time when changed
  - ○ Once a month
  - ○ Once a season
  - ○ Once a year
  - ○ Once every three years or more
  - ○ Other: _____

F Parasite related data

- ○ Dynamic Data (measure / capture)
- ○ Static Data (request / collect)

○ as INPUT

- ▸ Source of input-data:
  - ○ Primary Data, from _____
  - ○ Secondary Data, from _____
- ▸ Accuracy of input-data requirement:
  - ○ <50% ○ 50-75%
  - ○ 75-90% ○ >90%
- ▸ Frequency of (input-data) updates:
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  - ○ Once a month
  - ○ Once a season
  - ○ Once a year
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  - ○ Other: _____

○ as OUTPUT

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G Resources related data

Resources related data

a. Drug coverage (per area)
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d. Expert (per area)

H Other (qualitative) data

Other (qualitative) data

a. Frustrations
b. Improvement advice
c. Living environment situation
d. Working environment situation

- mission -

To maximize the effectiveness of health resources.

- Level of work in healthcare system

Community · Regional · National · International · Supranational

- Type of work and task

Field Practice ← → Strategy Research

- mission -

To give professional judgments in improving human well-being.

- Level of work in healthcare system

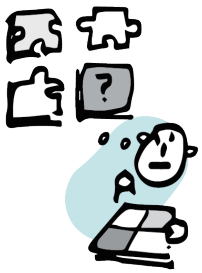
Community · Regional · National · International · Supranational

- Type of work and task

Field Practice ← → Strategy Research

- mission -

To ensure the development of comprehensive public health activities for the conutry.



- Level of work in healthcare system

Community · Regional · National · International · Supranational

- Type of work and task

Field Practice ← → Strategy Research

- mission -

To break new grounds in medical science.

- Level of work in healthcare system

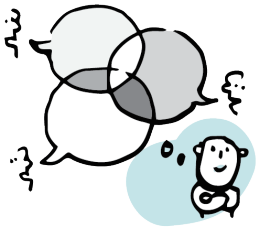
Community · Regional · National · International · Supranational

- Type of work and task

Field Practice ← → Strategy Research

- mission -

To build a healthier world for everyone and everyone.



- Level of work in healthcare system

Community · Regional · National · International · Supranational

- Type of work and task

Field Practice ← → Strategy Research

- mission -

- Level of work in healthcare system

Community · Regional · National · International · Supranational

- Type of work and task

Field Practice ← → Strategy Research

Offerings (WHAT):

Community health service

- ○ Adhere to policies and higher level behavior
- ○ Community serving
- ○ Linking between local context and health systems
- ○ Bringing Health solution in practice (Immunization)
- ○ other: _____

Methods (HOW):

- ○ Provide medically-related service in communities,
- ○ Link individuals to medical resources,
- ○ other: _____

- Keep track of the latest policy for disease control.
- Information about local medical facilitations.
- Understanding community needs & citizen health situation

Offerings (WHAT):

Professional medical judgments and actions

- ○ Medication monitoring and administering
- ○ Surgery performing
- ○ Diagnostic and treatment performing
- ○ Record and report maintaining
- ○ Patient care providing
- ○ other: _____

Methods (HOW):

- ○ Provide Healthcare with privileges,
- ○ Glving diagnostic to provide accurate treatments,
- ○ Assist medical practice,
- ○ other: _____

- Handling local disease epidemiological situation
- Medical and clinical knowledge
- Note and report special cases in the field for research

Offerings (WHAT):

Actions for health improvements of the nation.

- ○ Health-related policies, strategic plans, programmes.
- ○ Maternal, Adolescent, Child and
- ○ Reproductive health and nutrition services.
- ○ Solutions to improve the effectiveness and efficiency of health-related activities
- ○ other: _____

Methods (HOW):

- ○ Ensure all level of the healthcare, system is running smoothly within the country,
- ○ See the bigger picture from the national level,
- ○ other: _____

- Collaborative with service providers to figure out suitable strategies.
- Review of public health intervention financing and resource.
- Periodic review to ensure quality in related activities.
- Support, monitor and evaluate projects of regions, districts, and related agencies.

Offerings (WHAT):

New research breakthroughs.

- ○ Parasite and Infections disease study
- ○ Medicine, drugs, and vaccines development
- ○ Biomedical and biotechnology study
- ○ Diagnostic tools development
- ○ Prevention study
- ○ Specialist training and education
- ○ other: _____

Methods (HOW):

- ○ Provide education programs,
- ○ Support scientific studies,
- ○ Support expert research,
- ○ other: _____

- Monitor local disease epidemiological situation
- Analyze local disease report.
- Publish medical research studies
- Support the field of research

Offerings (WHAT):

Awareness and resources on a global level

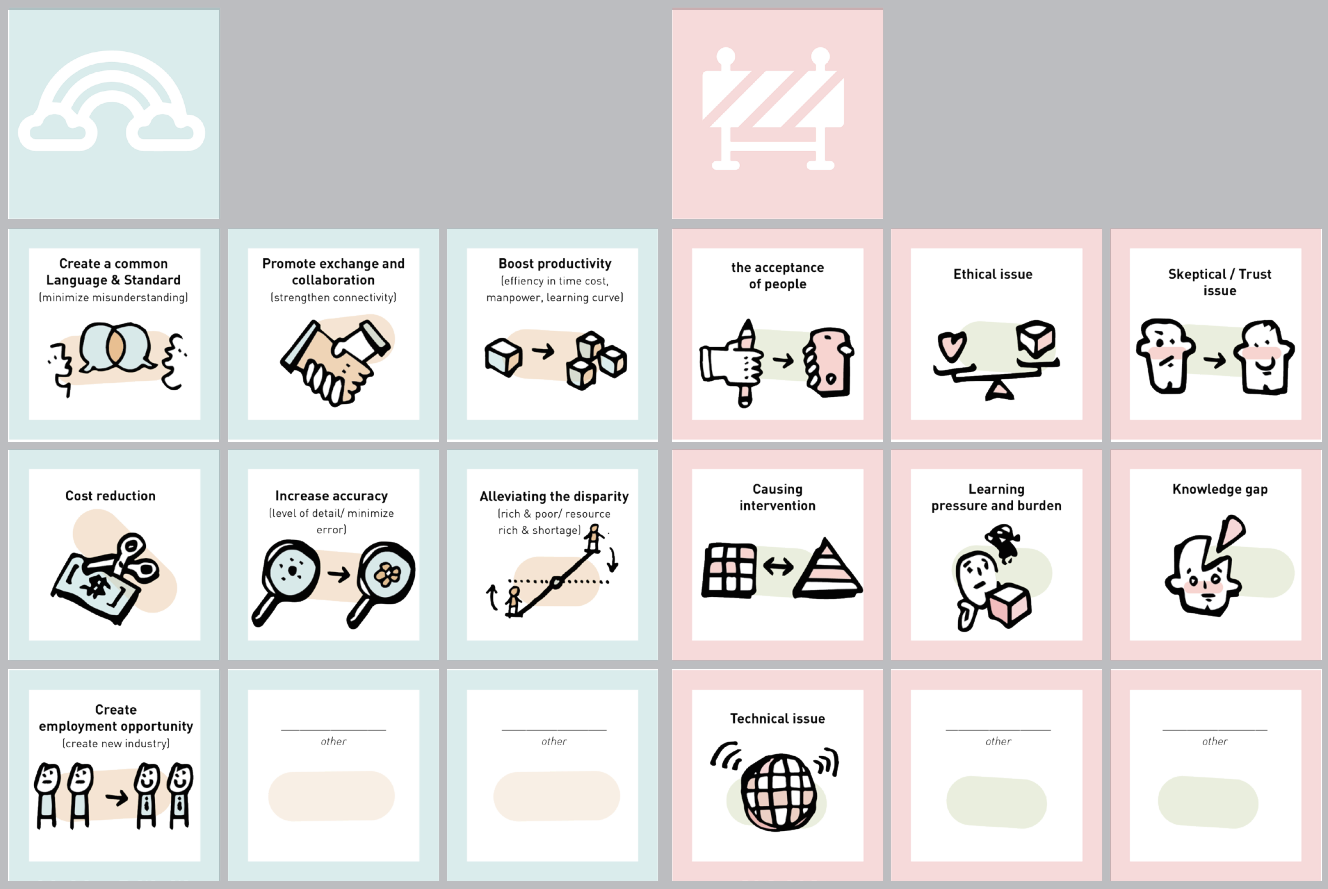
- ○ Health coverage promotion
- ○ Health emergency preparing
- ○ Prioritizing and promoting health in policies
- ○ Disease elimination study
- ○ Data monitoring
- ○ Health-related global action planning
- ○ other: _____

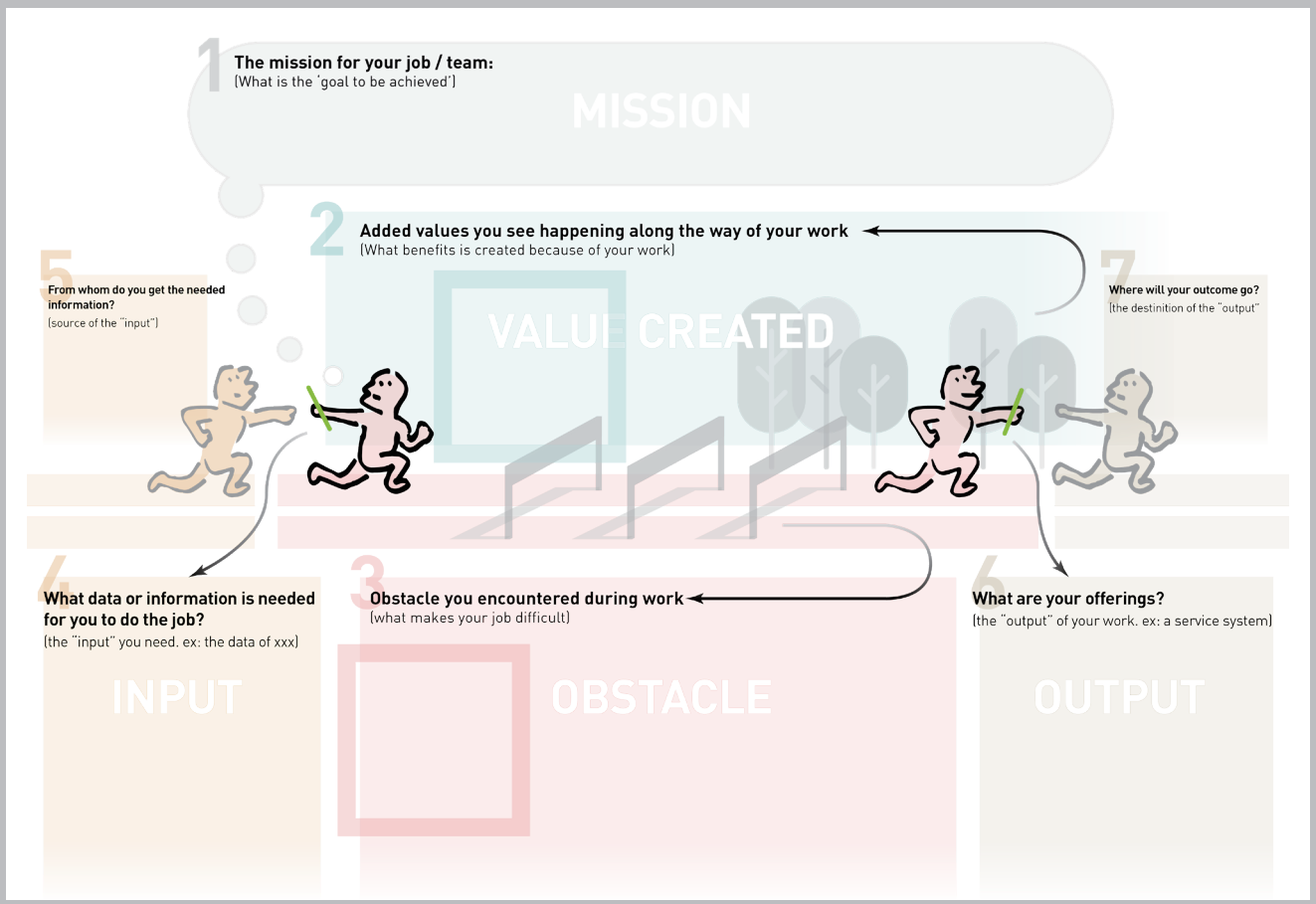
Methods (HOW):

- ○ Work closely with decision makers on a national level,
- ○ Support health-related influencers,
- ○ other: _____

- improve access to medicine and health product.
- support health-related policies
- risk managing for emergency
- disease elimination

A.b. Tool kits for data companies




1
The mission for your job / team:
(What is the 'goal to be achieved')
MISSION
2
Added values you see happening along the way of your work
(What benefits is created because of your work)
VALUE CREATED
5
From whom do you get the needed information?
(source of the "input")
7
Where will your outcome go?
(the destinition of the "output"
4
What data or information is needed for you to do the job?
(the "input" you need. ex: the data of xxx)
INPUT
3
Obstacle you encountered during work
(what makes your job difficult)
OBSTACLE
6
What are your offerings?
(the "output" of your work. ex: a service system)
OUTPUT

B. Risk factors' and 'remoting sensing data' for Schistosomiasis transmission

B.a. Risk factors that may influence the transmission of Schistosomiasis (Walz, 2015)

Parasite-related factors	Effect on schistosomiasis transmission
Temperature	Length of prepatent period; activity, survival and infection rate of free-living stages of the parasite
Water flow velocity	Passive transport of parasites in flowing water determines cercarial density
Predators	Fish and carnivorous invertebrates reduce parasite population as natural predators
Sunlight	Stimulation of cercarial shedding
Pathogenicity	Different strains of *S. mansoni* and *S. haematobium* result in geographical variations of disease severity
Species	Different efficiency in identifying and infecting snails
Snail-related factors	**Effect on schistosomiasis transmission**
Water temperature	Fecundity, mortality and rate of reproduction
Water flow velocity	Flow velocity >0.3 m/s may dislodge and swep away snails
Vegetation	Food supply, surface to crawl and deposit egg masses; increase of dissolved oxygen
Substratum	Nature of substratum is related to snail abundance
Water depth	Snails generally found in shallow water near the margins of their habitats; below 1.5-2 m, snails have little importance for the transmission of schistosomiasis
Fluctuations of water level	Permanence of available habitats determines the distribution patterns of snails
Rainfall	Creation of temporary snail habitats; increase of water flow velocity; supports contamination of water and passively transports snails when rains are heavy
Turbidity	Turbidity can impact the reproduction cycle
Water chemistry/quality	Low pH, refuse from factories directly harm snails; high abundance where water is polluted with human excrements
Sunlight	Completely shaded pools provide unsuitable habitat and activity of snails is high in direct sunlight
Predators/pathogens	Natural predators, parasites and pathogens may limit the abundance of snails
Species	Variation of susceptibility to parasite and efficiency to produce cercariae
Human-related factors	**Effect on schistosomiasis transmission**
Water contact behaviour	Exposure of the skin to parasite infested water is the prerequisite for human infection
Hygiene	Contamination of water due to excrements of infected humans in or aside water
Gender	Relationship between gender and risk of infection is culturally variable and a determinant of water contact activities
Age	Highest risk for children as consequence of degree of exposure and low level of immunity
Immunity	Resistance to reinfection can be developed by the human body as a consequence of previous infections
Ethnic origin	Variation in the susceptibility to infection
Religion	Religious rules related to water contact related to disease exposure
Socioeconomic status	Relation to hygiene, the availability of protected water supplies and ability to cope with the disease
Migration	Population movements can modify spatial patterns of disease transmission through both introduction of the parasite or the acquisition of infection
Occupation	Work related to water increases the exposure and risk of infection (fishermen, farmers, etc.)
Location of house	Location of house in relation to suitability of closest water source can influence infection status
Prevention/control measures	Spatial pattern of disease transmission can be highly modified by mass treatment campaigns and successful preventive measures

B.b. Remote sensing data for the transmission of Schistosomiasis (Walz, 2015)

	Factor impacting on disease transmission	Remote sensing (proxy) variable	Ecological impact
Parasite	Water body	Near and middle infrared reflectance	Hatching of eggs; infection of snail and human host
	Water temperature	Thermal infrared (emissivity)	Length of prepatent period; activity, survival and infection rate
	Water flow velocity	Topography: slope angle, curvature	Determination of maximal cercarial density; passive transport of parasite
	Predators	NA	Reduction of parasite population
	Sunlight	Shaded habitats (tree coverage)	Reduction of parasite population
	Pathogenicity	NA	Severity of disease in humans
	Species	NA	Different efficiency of snail infection
Snail	Water body	Near and middle infrared reflectance	Fundamental habitat of snail to maintain a population
	Water temperature	Thermal infrared (emissivity)	Fecundity, mortality and rate of reproduction
	Water flow velocity	Topography: slope angle, curvature	Determination of snail density; passive transport of snail; food availability
	Vegetation	Visible and near infrared reflectance	Food supply; surface for oviposition; increase of dissolved oxygen
	Substratum	NA	Abundance of snails in water body
	Water depth	Visible and near infrared reflectance	Abundance of snails in water body
	Stability of water level	Temporal dynamic of water body	Abundance of snails in water body
	Rainfall	Cloud thickness and temperature	Creation of temporary snail habitats; modification of water flow velocity; supports contamination of water
	Turbidity	Visible and near infrared reflectance	Reproduction cycle of snails
	Water chemistry/quality	NA	Abundance of snails in water body
	Sunlight	Shaded habitats (tree coverage)	Abundance and activity of snails
	Predators, parasites and pathogens	NA	Reduction of snail population
	Species	NA	Susceptibility to parasite and cercarial productivity
Human	Water contact behaviour	NA	Exposure to parasite infested water; contamination of surface waters
	Gender	NA	Determinant of water contact activities (culturally variable)
	Age	NA	Related to degree of exposure and level of immunity
	Immunity	NA	Resistance to reinfection can be developed following previous infections
	Ethnic origin	NA	Susceptibility to infection
	Religion	NA	Religious practices may affect patterns of water use
	Socioeconomic status	NA	Standard of hygiene; access to protected water supply; ability to cope with disease
	Migration	NA	Modification of spatial distribution of disease
	Occupation	NA	Work related to water increases exposure
	Location of the house	Settlement mapping	Exposure of population to potential disease transmission sites
	Prevention/control measures	NA	Modification of spatial pattern of disease transmission

C. Interview guide/interview notes

C.a. Interview Guide

C.a.a Healthy Entrepreneurs
C.a.b MSF (Doctors Without Borders)
C.a.c Erasmus Medical Center
C.a.d KEMRI (Kenya Medical Research Institute)
C.a.e Akvo

C.a.a Healthy Entrepreneurs

Small mapping exercise (with the blank radar sheet)

1. Where does HE see itself in this picture (In each level)?
2. What is the main focused area at the moment?
3. What is the current data/information flow in this picture? (followed up with Data related question in the interview)

Community-level (local healthy entrepreneurs)

4. Data Gathering: What kinds of data does HE currently collects from the field? Make use of which? For what purpose?
5. Technology infrastructure: The device, internet connection in the local site, Bluetooth..? Ex. What has changed (or will change) with better accessibility of the internet?
6. Touchpoints: What local connection does HE currently touch upon when contacting local healthy entrepreneurs?
7. Type of disease: How will be the data flow expected differently for a different type of diseases? Ex. Non-communicable diseases (diabetes, hypertension), doctors at distance programme, infectious diseases.
8. How is/will the local health entrepreneurs benefit from the data flow?

Country / District level

9. About giving professional treatment, diagnosis remotely/locally (doctors), how is it currently done under the system of HE?
10. What kind of disease is HE interested in (criteria of disease that HE is covering) (hypertension, diabetes) (Doctors at distance) in operating level?
11. How does HE keep track of their business with local entrepreneurs?
12. The integration of digital data and paper data, how is it currently managed?

National / Managing level

13. Is HE expecting any new project in the coming future? (If this is not asked in III Q2)
14. How does HE decide the next community to expand? → Criteria for the selection of the community.
15. Is HE looking forward to any kinds of upgrades in hardware and software? → Ex. Software capability, new sensors, better integration of diagnosis & consultation...

About information gathering, what improvements have HE made?
16. What kind of challenges and barriers are there?
17. Ethical/ privacy considerations for data collection and usage?
18. From your understanding, is there any other companies, NGO, or research center doing a related task in the field. (ex: Philips)
19. What kind of collaboration will be interesting for HE? (ex: university, research labs, companies, local government)
20. Can our research on data usage possibly benefit HE? (Link to the Next step)

Next Step

21. What is the desired position for HE (Use the mapping from II to guide)?
22. What medical optics can bring in that picture for infectious diseases?

C.a.b MSF (Doctors Without Borders)

About your job at MSF and with Akvo.

1. What are your primary responsibilities at work?
2. What do you think is the biggest challenge in working at low resource settings?
3. How do you observe the latent needs of your partners (understand what data need is necessary for the partner who you are working for.)
4. Do you see yourself influencing people's way of working in this picture of 'level of healthcare?

About the mission of MSF

5. What is the main mission for your team?

About information and data

6. What are your offerings at MSF and with Akvo? (your 'output')
7. What kind of "data" do you usually get in touch with?
8. Where do these data (survey question) come from? (secondary/primary data) (database? Literature? Field research?)
9. What is the format of the information or data you receive when working? (static/dynamic) (qualitative/quantitative)
10. Are there any critical criteria for information and data that you take into consideration? (accuracy of data, frequency of updates, details of information, amount of base numbers, source of information...)

11. What do you think technology can bring as benefit?
12. What do you think about 'new intervention in technology' interrupting the standard way of working?
13. About privacy and the owning of data, how is it managed in the field?
14. From your experience, how long do you think something new (ex: a new approach in working) can be completely implemented in low resource settings?

About being one of the players in improving people's wellbeing

15. Will MSF be interested if we have this smart diagnostic device that can collect diagnostic related data?
16. Is there anyone who continues to work with the outcome you created?
17. Are you able to influence WHO or governmental sectors at a higher level with the work you do? If yes, how long does the process normally take?
18. Do you see any problems in the current system? (ex: indirect communication, time delay, low awareness, tight in budget...)

About the ideal world

19. If there is no limitation in budget and resources, what do you think you and your colleague will be doing?
20. If any technology is possible, what do you expect your work to be like in the future?

C.a.c Erasmus Medical Center

About your vision as a researcher

1. In this position of your professional, what is your "vision" or "mission"? (goal)
2. To you, what is the most charming thing about doing parasite and (neglected) tropical disease research? (pains/gains, in response to what JC said about far from the field)

About resources

3. What disease-related data is considered "most precious" to you?
4. How do EMC currently collect research needed resources? (from fields / bigger organizations / other institutions / collaboration with ...)
5. What is the most important information that you value as a researcher outside the local field?

6. Do you or your colleague do field research? When is the progress is field research necessary? Who do you interact with? What do you collect? How is it done? How often do you do field research? What is the most important aspect of doing field research?
7. Do you ever find information from a local site "useless"? (what are those "useless" information like? Where is it from?)

About EMC as one of the stakeholders in this field

8. From your point of view, what is the biggest difference between EMC and a local research institution in countries? Is it the focus or scope the makes the biggest difference? (the role of EMC in the stakeholder picture)
9. What are the important information that you shared between research institution (output) Are you able to reflect yourself from this picture of information flow?
10. How much do you think the research you are doing affects low-resource settings practically? and how does the local situation affects medical research center like EMC?

About ideal situations

11. If there is no limitation in budget and resources, what do you think you and your colleague will be doing?
12. If technology can be 5-10 years in advance, what do you expect to improve from parasite and tropical disease research?
13. If anything is possible, what do you imagine and expect from TU Delft if we get to work together?

C.a.d KEMRI (Kenya Medical Research Institute)

Your vision in KEMRI

1. In this position of your professional, what is your "vision" or "mission"? (goal)

About resources

2. What disease-related data is considered "most precious" to you?
3. How does KEMRI currently collect research needed resources? (from fields / bigger organizations / other institutions / collaboration with ...)
4. What is the most important information that you value as a researcher?
5. What data do you collect? How is collecting done? How often do these data get updated? What format are these data?

About KEMRI as one of the stakeholders in this field

6. What is your relationship with the government, health workers, international research institutions?
7. What is the important information that you shared between stakeholders (output)?
8. Are you able to reflect yourself from this picture of information flow?

About ideal situations

9. If there is no limitation in budget and resources, what do you think you and your colleague will be doing?
10. If technology can be 5-10 years in advance, what do you expect to improve from parasite and tropical disease research?
11. What is your ideal world? What is the most important information that you value as a researcher outside the local fielde

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C.a.e Akvo

About your job at Akvo

1. What are your primary responsibilities at work?
2. What is the benefit of implementing your work at LRS?
3. About two types of stakeholders: development actions (long term focus) / humanitarian actions (action now). (the + & - of working as each)
4. What is the added value you see happening because of your work (blue card)
5. Do you see yourself influencing people's way of working on a different level?
6. What is the barrier for your job (red card)

About barriers

7. About privacy and the owning of data, how is it managed in the field?

About information and data

8. What input is needed for you to do the job (input)
9. Who provide you the needed information
10. What are your offerings at Akvo? (output)
11. Who continues to work on the things you conduct.
12. What do you think technology and digital data means to you?

13. Are there any critical criteria for information and data that you take into consideration? (accuracy of data, frequency of updates, detail of information, amount of base numbers, source of information...)

Other

14. About privacy and the owning of data, how is it managed in the field?
About healthcare or disease control, what do you think technology can bring as benefit?
15. What do you think about 'new intervention in technology' interrupting the standard way of working?
16. From your experience, how long do you think something new (ex: a new approach in working) can be completely implemented in low resource settings?

About being one of the players in improving people's wellbeing

17. Do you see any problem in the current system? (ex: indirect communication, time delay, low awareness, tight in budget...)

About the ideal world

18. If there is no limitation in budget and resources, what do you think you and your colleague will be doing?
19. If any technology is possible, what do you expect your work to be like in the future?

C.b. Interview Notes

C.b.a Healthy Entrepreneurs
C.b.b MSF (Doctors Without Borders)
C.b.c Erasmus Medical Center
C.b.d KEMRI (Kenya Medical Research Institute)
C.b.e Akvo

C.b.a Healthy Entrepreneurs

Q1. Data Gathering: What kinds of data does HE currently collects from the field? Make use of which? For what purpose?
A1. Mainly the number of needed supplies. Keeping balance financially and making a profit

is the goal for HE to collect data. Information can be used to monitor the sales, calculate expected sales, knowing what is needed... however, it is done in a really old school way. (ex: filling numbers in an excel sheet)
The data of disease is not collected. The sales of certain products are able to reflect the situation of a disease. HE can adjust the price if they see higher demand in a certain product.
Monitoring survey' is also done half a year to better understand the knowledge of the micro-entrepreneurs.
For HE, the most directly relevant data are 1. Sales. 2. The number of micro-entrepreneurs, 3. The number of videos watched.

Q2. Technology infrastructure: The device, internet connection in the local site, Bluetooth..? Ex. What has changed (or will change) with better accessibility of the internet?
A2. The speed of information is currently now a thing to deal with. Information transformation can be done via slow 3G internet. Hotspots will be brought to the sight when data transfer is needed. Calling is also an option, mainly used to keep in contact with the micro-entrepreneurs. Sms is currently not an option, it limits the type of data and it is also related to telecom companies, making it complicated.
For future: - A sim card with a little bundle of the internet. - Making it connected with their smartphone (when it gets to be more of a common thing in the future). (see Q12)
Internet infrastructure is much better in Kenya, even though it is considered as a new territory for HE in comparison to Uganda.

Q3. Touchpoints: What local connection does HE currently touch upon when contacting local healthy entrepreneurs?
A3. Call center with 3-4 people. They are positioned in between regional HEs and local micro-entrepreneurs. Calls are made regularly by the contact center to keep in touch with micro-entrepreneurs (cluster meetings), making sure these micro-entrepreneurs don't fade away. The officers in the call center talk about:

1. There is a clear list of questions (checklist) they have to go through to make sure these micro-entrepreneurs touch upon those topics throughout their business.
2. Comments are also asked if micro-entrepreneurs have any feedback.
3. Loans are checked.

The call centers are the touchpoints. They are the cluster. They are from the office and can be seen as sales officers. During the meetings with micro-entrepreneurs, they bring the products, synchronize the tablets.

Q4. Type of disease: How will be the data flow expected differently for a different type of diseases? Ex. Non-communicable diseases (diabetes, hypertension), doctors at distance programme, infectious diseases.
A4. Not specified, data are not stored according to disease type.
The data is collected mainly towards the goal of keeping the business running. Each micro-entrepreneurs have their own preference in what they want to keep in a record, -- even though HE gives them general training -- after all, micro-entrepreneurs are not working for HE, they don't have to report their business to HE.

Q5. How is/will the local health entrepreneurs benefit from the data flow?
A5. Knowledge increasing. Knowing more about the bigger picture can improve their quality in communicating with local citizens, which could help improve their business in

selling health-related supply.

Q6. About giving professional treatment, diagnosis remotely/locally (doctors), how is it currently done under the system of HE?
A6. “Doctor at distance”. Doctors are added recently added into the picture. Micro-entrepreneurs are asked to contact doctors for professional advice for treatment and diagnosis. However, this process is not done via HE. In Kenya, external doctors are working together with HE; in Uganda, doctors are arranged and hired by HE.

Q7. What kind of disease is HE interested in (criteria of disease that HE is covering) (hypertension, diabetes) (Doctors at distance) in operating level?
A7. It is currently based on what medicine are the entrepreneurs allowed to sell, which is quite limited. With the new “doctor at distance” model, the service is expanded. They are now able to sell products which were restricted by prescription.

Q8. How does HE keep track of their business with local entrepreneurs?
A8. As of Q3.

Q9. The integration of digital data and paper data, how is it currently managed?
A9. This is not really an issue for HE to deal with. Micro-entrepreneurs are left to deal with their business the way they prefer. Data collected by micro-entrepreneurs are for stocks and sales. For Micro-entrepreneurs, most of them don’t even see the advantage to do it digitally in the device.

Q10. Is HE expecting any new project in the coming future?
A10. New nutritious foods are always presented to the market, ex: soya power. Testing will be made before officially providing it. Also products like washing machines.
HE is thinking about providing micro-entrepreneurs smartphones, and allow them to use it for their personal life. Aside from making them more comfortable in using a digital device, it also makes using the smart device a part of their life instead of just for work-- this is definitely a trend.
Kenya is relevantly new as a country for HE. The decentralization way of working in the government made it easier for HE. Kenya is also having better infrastructure for Internet access. All these enhance the potential to work more efficient and active.

Q11. How does HE decide the next community to expand?
A11. Usually project-based, when HE is required to be in some projects that set them in a certain country. (Kanya is an exception, HE decided on their own. Kanya is always seen as a country for the entrepreneurial mindset.)
If HE is interested in a certain place, someone will be sent to check out the market. It is important to understand how the local market is functioning and see if the HE model has a chance to work there. Is it possible to make the small profit HE needs? Is making break-even points possible? Is there a need for creating a supplying point? The standard model doesn’t always adapt, changes have to be made accordingly.

Q12. Is HE looking forward to any kinds of an upgrade in hardware and software? Ex. Software capability, new sensors, better integration of diagnosis & consultation.
A12. Survey for micro-entrepreneur via a tablet. The survey includes understanding the needs of micro-entrepreneur, and education of new knowledge. It is now partly done via

tablet, but the situation could be improved.
Technology devices are getting cheaper, it is now easier to form people to get personal devices.
If internet technology really improves, the best thing is not about speed up the device, but to have doctors do distance video chats with patients -- this would be the priority.

Q13. About information gathering, what improvements have HE made? What kind of challenges and barriers are there? Ethical/ privacy considerations for data collection and usage?
A13. Keeping the number of sales up to date is one of the challenges. International shipment is minimizing, to reduce the complexity.
To get inactive micro-entrepreneurs active is another challenge, which is also related to profitability. →Data collecting could have a chance to improve this part, to see which part of the picture has to be improved.
For HIV testing, privacy is minded. Ethical training is also given.
Local people don't mind their data being collected at this point. Due to trust, this may also differ according to whom (which micro-entrepreneurs) customer gets in touch with.

Q14. From your understanding, is there any other companies, NGO, or research center doing a related task in the field. (ex: Philips)
A14. Livingood, NGO, focused mostly on urban areas. Livingood focused on the main branch, where HE takes the smaller routes into the rural area and really touch upon the locals-- more down-to-earth places that are even not on the map. →This is what makes HE unique.

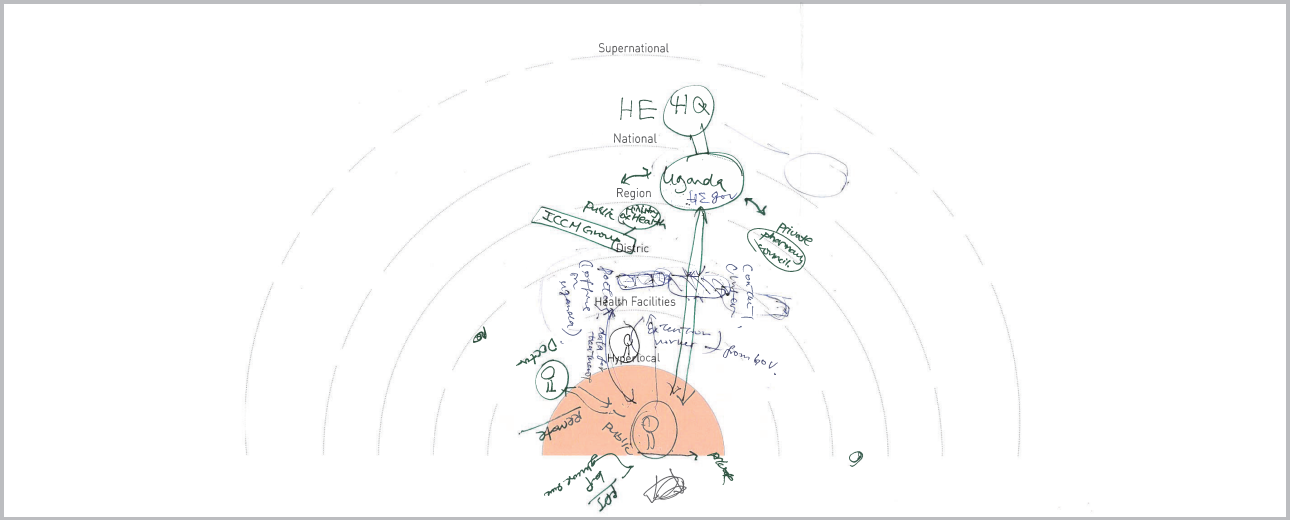
Q15. What kind of collaboration will be interesting for HE? (ex: university, research labs, companies, local government)
A15. Close relation with de VUmc. Recently there is a Ph.D. doing research on our product, to prove the model is working qualitatively, and thus improving people's motivation when they see the result.

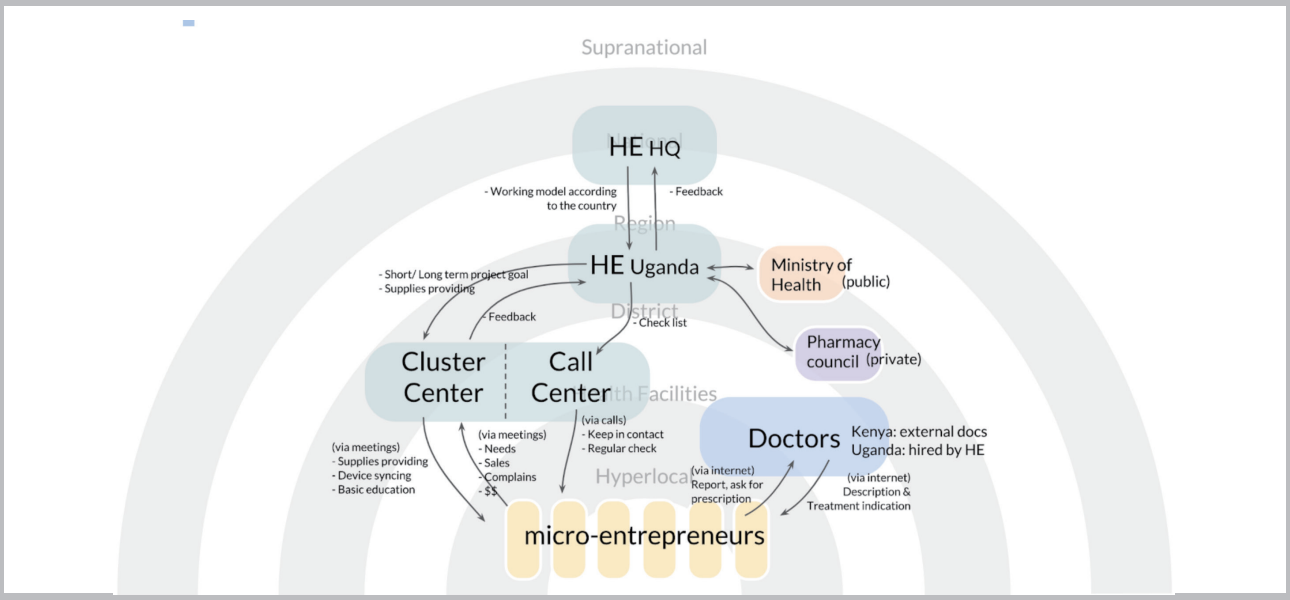
Q16. Can our research on data usage possibly benefit HE? (Link to the Next step)
A16. For local micro-entrepreneurs: They might be able to increase their business, service, and quality of work, as they can bring more certainty to the customer when they have more access to the knowledge form the bigger picture.
For HE: having data and make numbers talk will be a key to communicate with the government. (ex: reporting)

Other insights:

A) For HE, nothing is done currently with schistosomiasis.
B) There are two types of micro-entrepreneurs: 1. Like digital information, willing to document their business digitally, having less problem in using tablets. 2. Dislike digital information. Prefer paper writing when it comes to noting sales.
C) Business-oriented. HE is getting mainly stock and resources related information from the field. Health-related information is usually reflected by the need for supplies.

D) About collecting data via tablet, is more about the attitude of the micro-entrepreneurs. They are not comfortable in keeping stocks and sales with their device yet, even though the tablets' software sort of provide such function, such a behavior-changing requires training, which takes time. Currently, the training of tablets takes only one day.
E) Potential data: It might be interesting to also know more about the sales (data) of the entrepreneurs, the number of people they reach vs the number of product they are selling, and the price they are selling it. The information from "the doctor at distance" can also help since it is now introduced to the framework.
F) Kenya is much more decentralized, things are on the district level, making it much easier and flexible, as the approval don't have to go all the way to the government. In Uganda, everything still has to go through the ministry of health, and things need to be approved through the entire country.
G) The information from doctors is also checked regularly by HE, in order to get a better understanding of how many new patients are there (data).





C.a.b MSF (Doctors Without Borders)

FINDINGS:
F1: Consortships in development sectors. MSF is not part of them.
F2: technical issues can be a big part of barriers, (internet, electricity...)
F3: Implementation of the projects can take some time five years if it is a development project.
F4: NGOs like UNICEF and MSF doesn't collaborate. They talk with each other to make sure if a certain part of the task is already covered in a country or not.
F5: Organizations like MSF will have to be accepted by the government and higher authority in a province, to be able to provide service. Regulation in different places will influence their work.
F6: The benefit of conducting digital data collection rather than paper: minimize hand-writing errors, different types of questions, add in logic orders and skip questions, and forcing people to finish to ensure completeness.
F7: it is difficult to be totally anonymous. Having four touchpoints in data transmitting can already expose private information.
F8: Sharing data can give people with bad intention lots of chance. It is important to have a clear goal of what is the reason for data sharing and share only the necessary data.
F9: Qualitative feedback can be sometimes more important than quantitative data. Qualitative data help adjust approach, (matching the finding from Federica)
F10: two types of stakeholders: development sectors – focusing on long term/ humanitarian sectors – focusing on the action now. The processing time may be different. One may be slow, and inefficient but honest.
F11: People in between can be a barrier to the usage of data. Data can be very hard to read, but timeless can be very important in data usage. Very often people who can read the data is not the people who know how to act upon. Transforming data into results for end data beneficiary can boost efficiency (← time, money. Resources..)
F12: Security can be a barrier to the usage of data, reducing the ability and advantage of data usage.

Q1. What are your primary responsibilities at work?
A. I moved to Kenya with YEP (young expert program) from the ministry of the foreign affairs, they send out young people to different developing countries in the water sector, Akvo operates in the water sector as a data enablers, they develop software for data collection and data analysis. I went to east Africa, Kenya, where I gave training in the software as well as user testing with the product to improve our testing.
It could be facilitation sessions with small NGOs or big banks. It is a lot focused one water sectors, as well as the disability sector, for data collection.
With MSF, I am part of the displacement unit, as an innovation unite, and focus on display people population internally, for example, refugees, migrants, all types of moving population. We work with all kinds of field mission worldwide, also in South America and Southeast Asia. If they have any questions and ideas, the team they can reach out to for pilot, experimenting with new ideas, solutions, and testing.
It is a big corporation. We have people that have been working for 20-30 years and are not

fond of a new approach.

Q2. What do you think is the biggest challenge in working in low resource settings?
A2. Internet issue access. The government may have shut down, which we have to set up VPNs. Also electricity. It can also be in the field, so we also have power banks.
Acceptance: it is a lot with the skills with people interviews. Younger people are more motivated rather than we paper survey. Older people are more reluctant.
A big pitfall is having too many data, by having too many questions that you cannot act upon. So it requires good thinking upfront: what you want to know, what can I actually use. Which can be both tiresome for both beneficial, and the interviewers, which can also make people not so much engage, and creating inadequate data, and having too much data to analyze.

Q3. How do you observe the latent needs of your partners (understand what data need is necessary for the partner who you are working for.)
A3. The people who I train to conduct the survey are third topics. They are often not on topic.

Q4. Do you see yourself influencing people's way of working in this picture of 'level of healthcare?
A4. We are not working so much with health sectors, but civil society. A lot of time is "big consortship", a group of actors together who do a program. International NGOs, local NGOs, civil society organizations, governments, sub-county governments (with lots of powers, sometimes have different regulations).
The beneficiary that will eventually come to will be the local community. The use of the data is by the organizations. With Akvo, we work with all of them on the map, but with MSF, we work with none of them, In practice we do, but we are not collaborative. We do not operate as a consortship. If we are on the ground, we have UNICEF, we talk with each other, but we have different tasks. We don't work together. We only make sure the thing we are doing is not also done by someone else already.
The top layer of supranational organizations, they can actually be divided into different levels: Headquarters who does the guideline, and also implementers, ex: IOM (an international organization of migrants) they also make guidelines, but on the ground, but not up there.
Before MSF enters the country, the government always has a big saying, and you will always have to ask for permission. A lot has to do with advocacy. In sum: country government to enter, and sub government, local communities.

Q5. What is the main mission for your team?
A5. For Akvo, a service provider. We always work together with the organization. The mission is more depending on our partner organization. It is a lot about accountability, evaluating (is planning and outcome matching; midterm or annual evaluation of frameworks). Based on the indicators, and the measurements you take, you can steer the project. Ex: adjust strategy by looking at the outcome, and dig deeper into what is happening, and no what directions to look into. This is always a project with a partner (instead of a client).

Q6. What are your offerings at MSF and with Akvo? (your 'output')
A6. Surveys are the tool, data is the output (as a dashboard, an excel...), the advice is added

service. We give advice in approach to doing a survey to companies and NGOs.

Q7. What kind of "data" do you usually get in touch with?
A7. Akvo, as a service and technology provider, they provide the survey to get the data. We are provided the survey, and we enter them in the dashboard, then we go together with the third party, where everyone has a mobile phone, and we teach them how the software works.

Q8. Where do these data (survey question) come from? (secondary/primary data) (database? Literature? Field research?)
A8. The consortship creates it. They have a formal indicator ex: in five years, we will have to reach a certain goal. Base on the target population, KPI. Depends also on the framework. MnE people (monitoring and evaluation) will create the survey.

Q9. What is the format of the information or data you receive when working? (static/dynamic) (qualitative/quantitative)
A9. It comes in a dashboard, or big excel sheet, with data analysis. In Akvo, they have data analyst, so they can advise the organization on how to make good use of the data as an added service: how can you use the data (a book of data-driven design)

Q10. What do you think technology can bring as benefit?
A10. Cost reductant. Boost productivity with efficiency in speed. There can be a lot of practical things, for example, handwriting errors, papers are heavy to carry, the digital survey you can also do skip logic, and different types of questions. On paper, people can shift questions, with digital you can force people to answer, so you have a more complete answer.
In Kenya, mobile penetration is high. People are used to technology and can be used easier.

Q11. What do you think about 'new intervention in technology' interrupting the standard way of working?
A11. Having a common language: Yati – standard for data. You can comply with data, a set of terminology, you can stimulate and encourage in reporting in a certain terminology, as this is a big thing for data collection. Different word using will make it really difficult to compare data between different platforms and organization. There is also advocacy to make your data open-source. You can also say "Yati complied, and I am opening on my data" you can find data from every organization, that report on that format. It is currently focused on the water sector.
With healthcare, there will be a whole different thing in open source, but instead confidentiality. You may exchange data but will not clinical data (not on an individual level), and keep it anonymous.

Q12. About privacy and the owning of data, how is it managed in the field?
A12. A few days ago, on BBC, hackers targeted and aid organization on WhatsApp. It is important to not communicate through these channels of theoretical data. Four data points make it possible to trace back. Even though the action itself is an anonymous thing, all the channels that have to go through are still counted as a touchpoint.
MSF should invest more in data privacy. It is currently not the expertise of MSF, Privacy is getting more relevant if we are using technology more often. Positions are created because of this.

The awareness of data privacy varies, where organizations may care, but the people doing the survey and are collected for data may not. There was a very big data security discussion with MSF in London last week, asking for consent. If we do a pilot, we have to make people understand it is a pilot, ..., and do some balance between "doing good and limiting yourself" being too ethical and cannot provide care to people that need help, that is not what we want to see.
Not storing the data in places like google drive, dropbox, and online amazon memory online. We make sure our client knows where we data is stored, and let them know that they are the only one who has it, and we will not share it.

Q13. From your experience, how long do you think something new (ex: a new approach in working) can be completely implemented in low resource settings?
A13. First of all, they do take the advice from Akvo into implementation, as it is usually a program project with a lot of money. The implementation time depends on what kind of program. A development program can take five years. During the stages of the project, they analyze the data, adjust the program, after five years, you get the result step by step. The advice from Akvo it mainly how to use the data, instead of approach. The advice is given as a "conclusion". If the data shows a certain pattern, Akvo can highlight it and point out what to look into.

Q14. Will MSF be interested if we have this smart diagnostic device that can collect diagnostic related data?
A14. My first idea is: No. MSF will not want to share the accumulated data.
We as Akvo, we are actually the same position as you, the smart diagnostic device provider. We do not own the data and will not say that we will share the data. In this case, if you are looking for something of learning with each other, it should be clear what is the goal of sharing. why should be sharing the data, what will we do with it, will it feedback in policy, who will it be shared with? (reference in a certain topic of certain disease within MSF that will be shared with)., what data will be collected, what will be stored,
In terms of automatically sharing and collecting, it can already go too far, as we are assuming people do good with these data
Statistic on disease may be interesting compare to location. Direct influence on a higher layer, may be interesting. WHO do advocate for some guidelines, so they may be interested. But still, be aware to limit and define what data is necessary to improve the guideline (only share what is necessary for the purpose, instead of sharing everything, only what Is necessary)

Q15. Do you see any problems in the current system? (ex: indirect communication, time delay, low awareness, tight in budget...)
A15. The reason why people do the survey, reason 1: to keep monitor, reason 2: they have to report to the donor to get money. MSF will not have the obligation to make such a big report if the donor is an individual instead of government or organizations. And this is why MSF does not have the MnE framework. I would suggest MSF collect user feedback (currently on food), to get a bit more qualitative result: Is the item MSF is providing good? MSF doesn't necessarily need to ask a hundred questions to know the result.
For advice, there can be a difference between development sectors, and humanitarian sectors. Development sectors are normally for long term program, Humanitarian sectors are focusing more on the action now. SODOS feels more for humanitarian sectors, which are health care providers, not making programs. On the long term, you have WHO who makes all these guidelines for certain purpose.

We can argue there are so many meetings that make it a long process, and so many tenders, ex: putting things in public, everyone wants to do data collections, you have to select data...
On the other side, all these reporting may seem inefficient, but more honest, since you will have to publish it.

Q16. If there is no limitation in budget and resources, what do you think you and your colleague will be doing? If any technology is possible, what do you expect your work to be like in the future?
A16. If there is no security, then every data will be reachable everywhere, even already analyzed in a nice graph, and already fulfill you your direct expectation timelessly, ex: already telling you what to do as advised.
Akvo also has a sensor that can detect the quality of the water (ex: ph), which can already be a timeless result for people who are interested in knowing how to act upon.
Barriers to data usage: 1. Privacy, 2. The amount of actors in-between: the one who reads the number is not the one who knows what to do with these numbers. Only when the data comes back, then you know what to do, but by then you already lose a lot of time. When a researcher is separate from a specialist, can be time-consuming... ideally, the data can be directly interpreted into meaningful information to the benefices themselves, boosting efficiency in time, money, and resources.

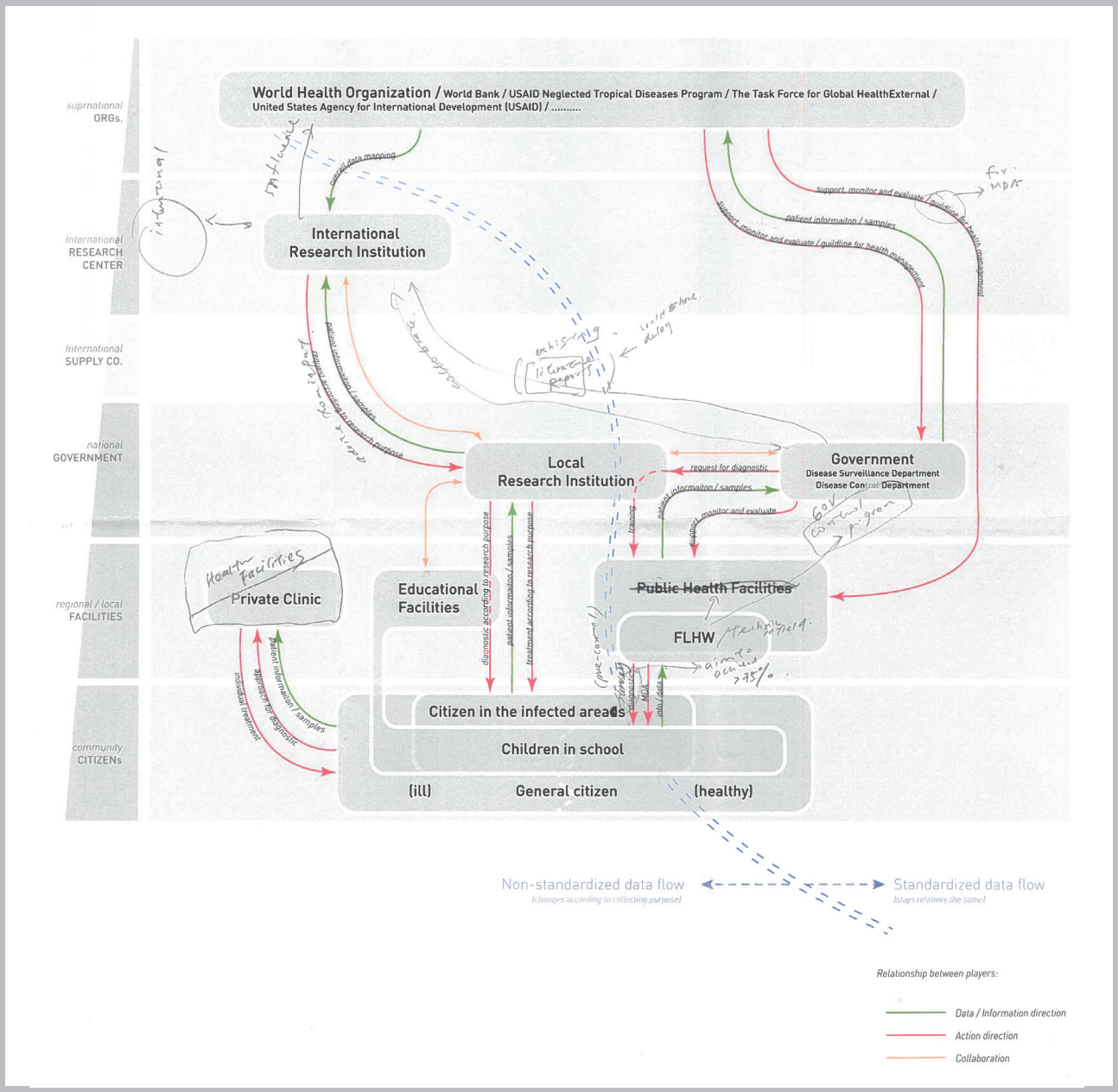
C.b.c Erasmus Medical Center

Highlight findings:

F1: For neglected diseases like Schistosomiasis, public health care from the government is a much more important player compared to health facilities. Health facilities are mostly for notifiable diseases. (see Q2)
F2: Disease controlling approach can be generally divided into two: 1. Active detection 2. Passive detection. (see Q3)
F3: All the modeling and research is aim to ultimately influence the local field.
Channel 1: To WHO- how to adjust guideline and strategy.
Channel 2: To local research institutions- how to adjust the research approach. (see Q7)
F4: There is a time delay in communicating and advising the local field. The communication flow is indirect, and not straight forward. (see Q6)
F5: Drug adherence is hard to know. (Out of those who should be treated, who is truly treated). (see Q9 Data C)
F6: Limitation for MDA:
1. The data is hard to be on an individual level due to the collection process, however, a rough estimate about population segmentation (ex: by age), can be a big help to modeling and researching. (see Q9 Data C)

2. There can be a gap of information when the survey testing is only done before and after the complete MDA process (which takes years). This makes it hard to monitor the controlling process. (see Q4)
F7: "Repeat testing" can improve the depth of the research. It is more important to know the day to day variety of data, instead of before or after MDA. (see Q9 Data E)
F8: Data is collected for two purposes:
1. To further understand the situation. 2. To predict the future. (see Q9 Data F)
F9: Qualitative data like frustrations and advice from the local field or citizen can help interpret the result. (see Q9 Data H)
F10: Low limit detecting in infection intensity is a threshold. Hard to set a criterion (N-/N+) for "elimination achieved". (see Q10)
F11: The key to ultimately eliminated Schistosomiasis:
1. Short term: ensure MDA implementation.
2. Long term: improve infrastructure hygiene and change people's habit (see Q11)

Interpretation of how disease controlling is happening in the world -- the information and action flow between different level of healthcare.



Q1. Can you relate the work of yours in this map?
A1. This map can be on a general level, theoretically for different countries and disease-- some minor changes if it is the case for different countries and neglected disease.-- some arrows disappearing.

Q2. For the information (green) and actions (red) flow for Schistosomiasis, can you relate?
A2. In many disease cases, the direction of data starts from where the citizen is, and then the direction of information flows upward. But for Schistosomiasis, many time people don't seek treatment, as they don't even know, and might not have symptoms.
For schistosomiasis, there are control programs, so the information from citizen don't actually go through health facilities, it will be the government-- doing surveys to try to understand how many people are infected in a certain area. The population will be tested via sample (urine) testing, particularly children. Control program implements it and goes through health workers.

Q3. What are the common approaches in disease controlling?
A3. As mentioned, for a neglected disease like schistosomiasis, there are control programs from the government. The information from citizen will not necessarily go through health facilities. Health facilities and more for notifiable diseases or new cases, for example, malaria, dengue, Zika. Malaria sometimes shows only a few symptoms, so it can be also the case of both.
The approach can be generally divided into two:

1. Active case detection -- health workers goes to the field and run a survey, try to take a "snapshot" of that time point for the infection.
2. Passive case detection -- where the public health facilities wait till someone goes and seek treatment. (people have symptoms)

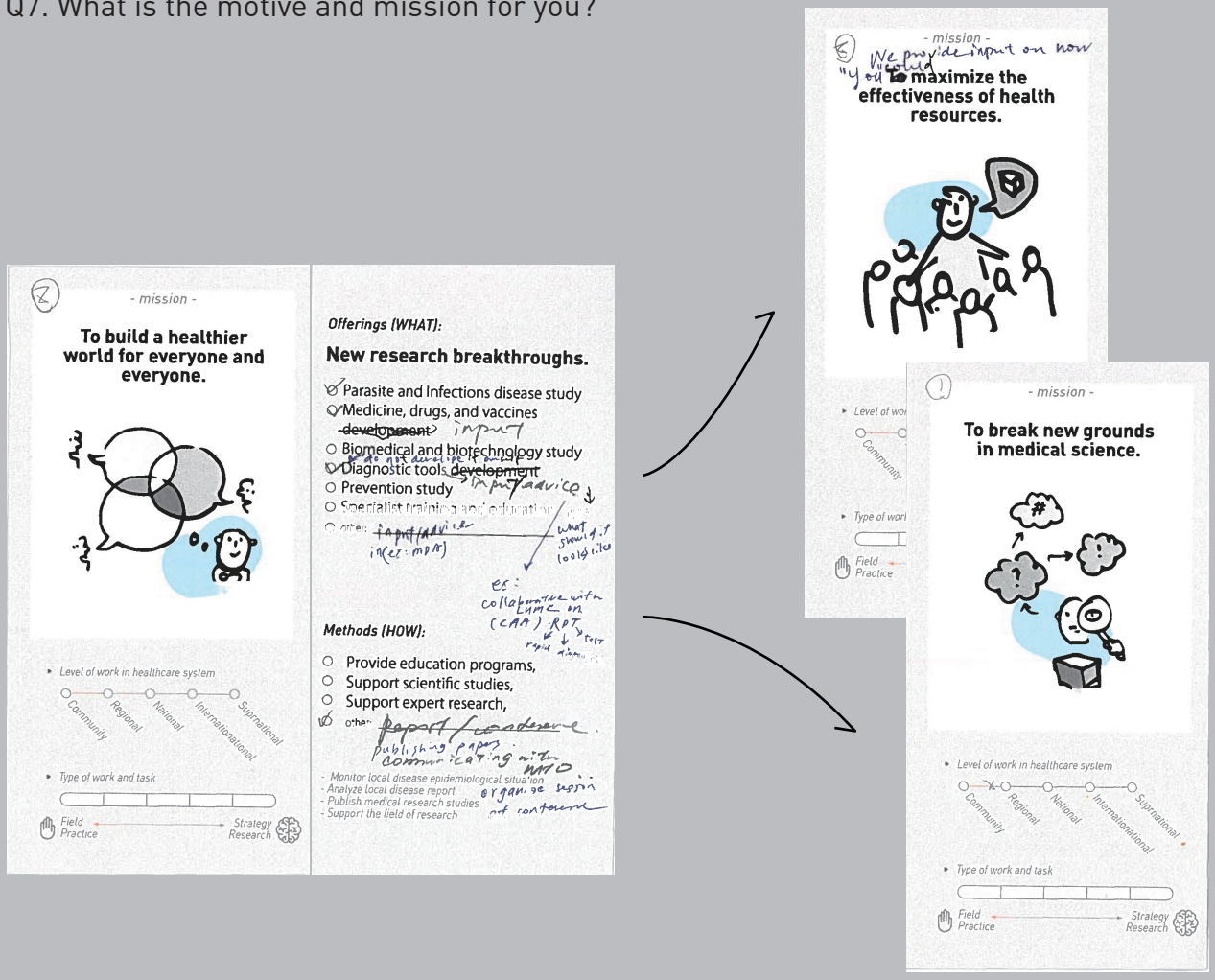
In the case of Schistosomiasis. Really bad if the high intention or repeated infection on children. People wait till the MDA comes.
The control program decides on the size of the group (often school-age students, 11-15 years old) they want to test before they give MDA. depending on the prevalence, which can be referred to the guidelines from WHO, different MDA program will be given (ex: Drug annually for five years).

Q4. Do you see any problem with the current survey-testing & MDA process?
A4. With testing and treatment, they only get to do MDA.
The first assessment (via a survey) is used to understand the baseline prevalence (pre-control prevalence). Based on the prevalence they have access, they then start MDA -- this assessment is then done at the end. According to the MDA guidelines from WHO, the aim is to test everyone (over 75% of the population = school-aged students)
Some area (the ideal situation), another assessment will be done every time before the MDA, which will end up having 5 different prevalence in 5 different time points. (if the whole MDA is a 5 years process)
In some area it doesn't happen, so you only get the beginning (before MDA) and after (when a certain year of MDA is done) which is not ideal for the monitoring of the effect of intervention, as it is hard to know what is happening in between, hard to know about outraged infection, or how is the trend going. However, this is also not clearly mentioned in the WHO guideline.

Q5. Who examine the samples? Who makes the call?
A5. Health access the samples, they are local people, technicals. The diagnostic process is standardized. Health workers are appointed by the control programs or the health facilities (which is content dependent.)
Whoever is giving the funding (including the drugs) will influence the guideline-to-followed as well. It is not always WHO, sometimes they follow the guidelines to whom donates the drugs, once the drug is sure received, it is passed on to the FLHW to be sent to the field.

Q6. How do you get information from the field?
A6. Information from the field is never the samples because we never test them, we don't do any lab work, we do analysis -- sophistically statistical-mathematical-modeling on what comes to us. What comes to us can be either through local institutions, or via from the control programs (government), or very often from literature (existing published papers).
Most people who go to the field for assessment, the make description of the situation on sight (method, accessing principle, prevalence after running MDA), report the result, public the paper.
Gathering data through published report will result in some delay in output in formulating the result and giving advice.
Direct communication with the people in the field is not straightforward. We will like to collaborate more. Even though it is suggested, it will not be implemented in the field right away-- it is a long process.

Q7. What is the motive and mission for you?



A7. The ultimate goal will be to ultimately influence the development of the policy guideline from a higher level. We communication with WHO, who develops the guideline and share with the control program. By talking with the WHO we have an impact on the people (indirectly).
With our modeling work, we get information on the right side (of the map), but we want to provide input to whoever that develop the guideline, "look, if you do this intervention, and how often you do it, with what coverage to improve the health of the population, you will improve their lives, and achieve SDG (sustainable development goals)..." which not only improve health but also improve the economic situation.
We communicate with them, so with the language we speak, and who can actually make the decision, we are able to influence the policy development and the guideline. In the ideal situation is, after all, following the guidelines of WHO, so this is the ultimate goal of the modeling.

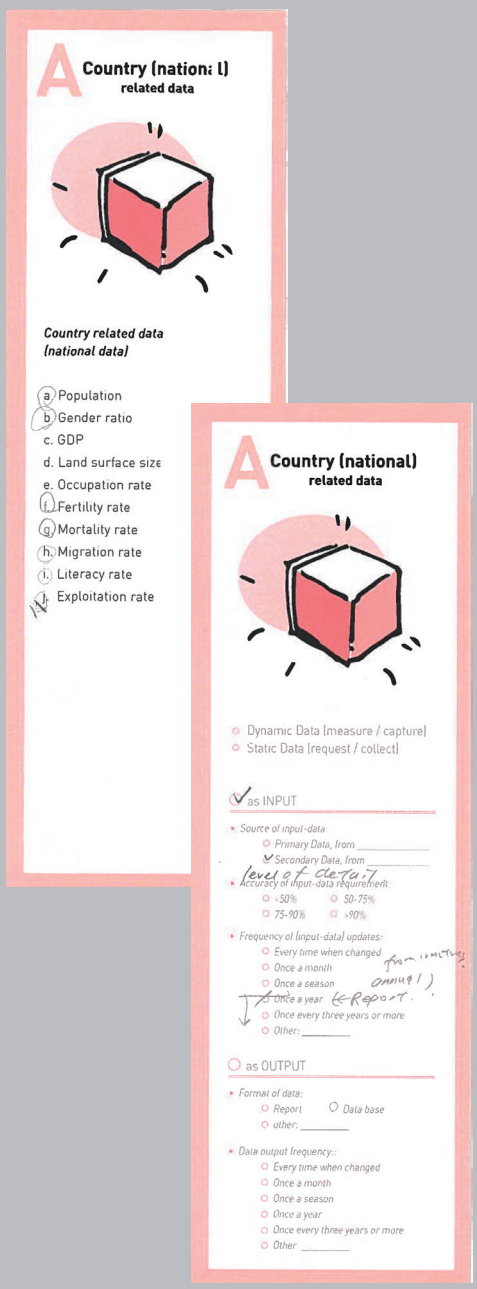
(Card 1) Modeling is to first understand how the disease controlling process works, how the infection and transmission work in the population, but you will only be on the level of understanding if you don't translate it into the application from the practical point of view, otherwise, it will be useless, and will not bring you closer. In this case, they will be able to provide feedback to the WHO, as they are holding this umbrella.
In the perspective of the data, we will be able to influence the local research institution, as they are very often the one doing fieldwork. As an input, we can tell them there is a need to for example collect more data on this because based on the modeling we do, ...
Since the road to influence the world is so complex, the first step will be to understand what is going on, so it will be the mission of " break new grounds in medical science" --the first step.
A mathematical model can help you understand what is going on, but at the end, it is very applied work, otherwise, it will still stay on the level of exercise, as "oh, yes, I understand these because my model tells me this". So translating the understanding into practice is really important.

(Card 2 and 3) If we are a mathematical institution, we will only stop at the first step. However, everyone in the field is worth to share their results with the world, to answer the question 'why are we doing this'.It is true that we want to get close to the truth and want to understand things from a scientific point of view, which is indeed there, but there is also an applied side in our work.
The ultimate goal is not about understanding the situation. So it will be: 'We provide input on how 'you' could maximize the effectiveness of health resources". After we understand the situation, we want to provide input to do all the other things! And "build a healthier world for everyone and everywhere".

Q8. What are your offerings and how you actually do it?
A8. a) Parasite and infectious disease study.
b) Medicine, drug, and vaccine development advising.
c) Diagnostic tools advising.
For diagnostic tools, we don't develop it ourselves, but we provide input and advice on how it should look like, for example, with LUMC (CCA is already been developed RDT, rapid diagnostic test, based on the detection of antigens) they are now working on CAA. Together with them, we are trying to understand what should be the characteristics of

such a diagnostic, as it is highly sensitive, which can detect light affection, and can thus be also expensive. It will be challenging to produce rapid diagnostic test on this. We will do some modeling on this, trying to know what we will get if we do an adjustment. (ex: cost, sensitivity, quantitative or qualitative...) -- modeling to inform them of the modeling of diagnostic tools depend on the purpose.
We also give input on how many rounds of MDA should be given to WHO.
e) Via report, papers, conference.
As for channels, we produce reports, talk at conferences, publish papers.
We also have a strong link with WHO, so join meetings with WHO, organize sessions at conferences.

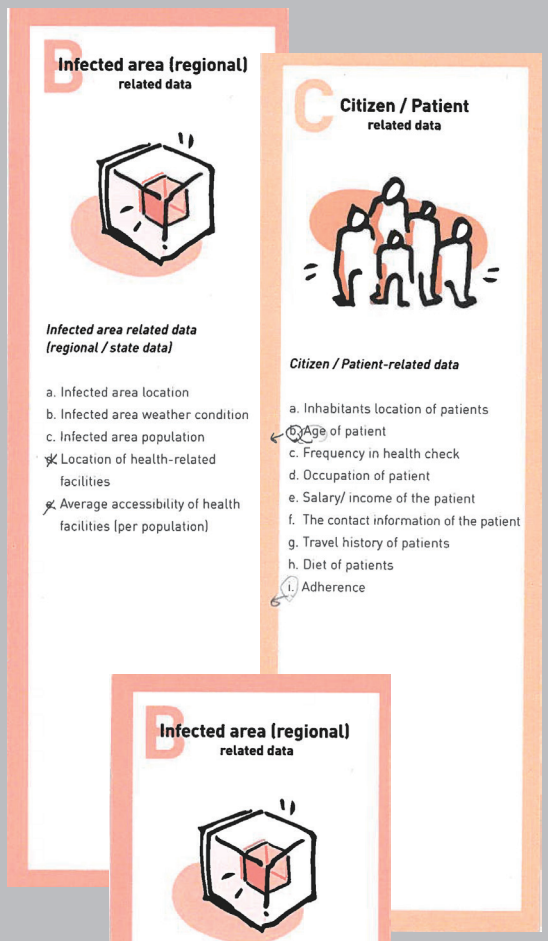
Q9. What data is relevant to you? (input / output)

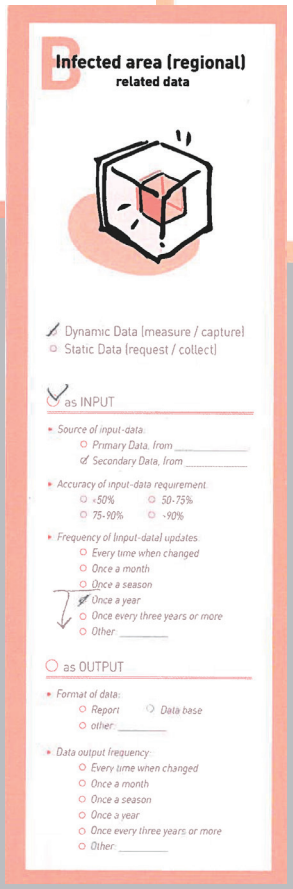


A. Country related data -- Easy to get. Annual. Seldom changes. Important to be detailed then to be accurate.
As data from a country level, these data are easy to gather. Important as an input, but it is not from the field and it will not change easily.
It is all relevant depending on the disease. For schistosomiasis:
V Population
V Gender.
Gender issue can be potentially interesting for some studies. There is some mobility in Schistosomiasis that is related to the infection in a female.
V Fertility
V Mortality
V Migration
The movement of population is also believed to be influencing the detergent of the disease in some of the settings. There will be low transmission if people stay in a location.
V Literacy
Literacy rate can be linked to education and related to how much people know about the illness, which is related to the efficiency in prevention.

-INPUT-
V Dynamic Data V Static Data
Data can be seen as static and dynamic.
We have the population size (static) at a certain time point, it can be enough to have a rough estimate to what the ... is -- to make it become 'dynamic'.
For my work, I do stimulate the population over time, but it is seen as a bigger picture as "Static".
x accuracy | o detail
Instead of the accuracy in numbers, will be about the detail that is important. How is the transmission pattern? how big is the population? (The composition

of the population pyramid) Which section of the population are children?
V Annually
For country data, we never get in from the field. They are publicly available. It is online and on a country level. It is normally gathered once a year. We can update and repeat our analysis easily.
But more likely from year to year, not much will be changed, unless there are conflicts, big migration, or refugee.



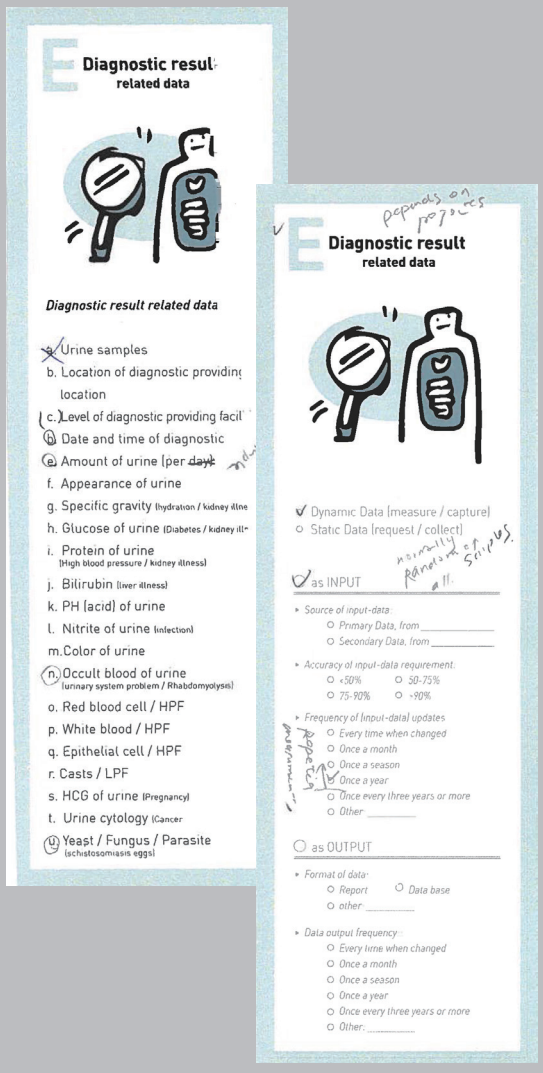


B/C. Infected area data / Patient data -- Hard to monitor due to current MDA limitations. Annual data input will be already very good.
These are all relevant for disease generally, but for Schistosomiasis, the location of the health facilitation and accessibility of health facilities is not that important, as people seldom seek treatment on their own.
V Infected area location
V Infected area weather conditions
Weather condition is important in the sense of ecology, as it is relevant for intermediate host -- the snails.
V Infected area population
V Age
Age is important for the composition of the population pyramid.
V Adherence (coverage)
For adherence, following up is not an issue, after all, there is only one tablet. But are people really following the treatment? In practice, we don't really know how high is adherence. You still want to have a measurement of how many people actually took the treatment, out from the one you wanted to treat (took treatment / should be treated %)

It is hard to know 1. You don't always manage to treat all that you wanted to treat (should take but didn't take). 2. Is it always the same people that are not taking the drug, or it is just a random population.
It is different to know this information on an individual level, but at least a measurement can be helpful. It may be possible to know who should be taking the survey (and MDA) but didn't, but however hard to know if they took it but didn't swallow the drug.
In terms of "coverage", it is in the guidelines of WHO--→75% of coverage. However, the measurement of this is currently a rough estimation and done at the country level. Even though it will be best to have the "coverage" (adherence) data collected at an individual level, but on the level of infectious level should be helpful.

If it is not able to have the data at an individual level, (age of single patients, adherence, reinfection), at least the fraction level of the population (children/adults). The adults are very often neglected, so whether the adults are treated is also interesting.

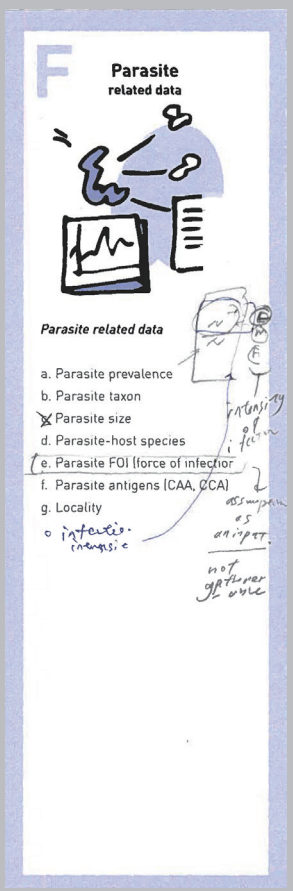
-INPUT-
V Dynamic Data
V Secondary data
I never go to the field and collect data by myself, but I may get data that are collected by someone else aside from public health, for example, other international research institution, or local health workers.
There are other international research institutions that collaborate with the local government or local institutions. I also gather information from them.
Ex: Glasgow research institution, they have field workers in Uganda, working on the reinfection rate of people, and how often people reinfect after they are cured.
V Annually (stimulation of data happens at the end of a time scale)
In a given setting, MDA is assumed. Infected related data can vary every month, however, data is not received every month, it more common to get data every year, and that is already enough.
Stimulation is done at the final time scale, as there is a lot of processes happens by month, for example, the life span of worms. Data input is updated more often yearly.

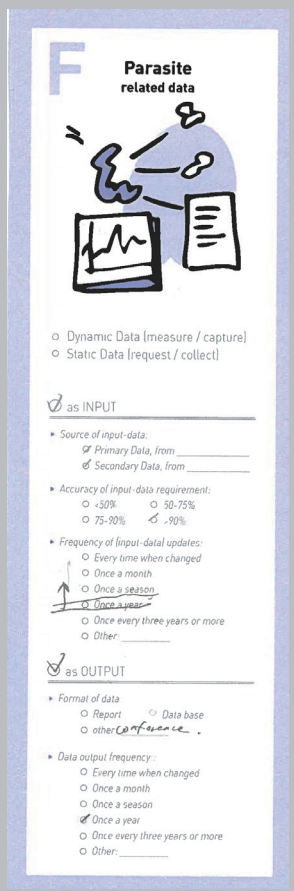


E. Diagnostic result data -- Data by repeat testing can help improve the illustration of the scenario. Preferably updated more frequently instead of annually.
Very often, the diagnostic process is not always reported. For Schistosomiasis Haematobium, it is urine or POC (point of care CCA)
The urine sample is not relevant to us as an international research center.
"Level of diagnostic" is not always relevant. When a sample is tested, it is done in the local lab. This local lab can be a temporary one in a rural area at the field especially if it is urine-based (as well as Kato-Katz for Schistosoma mansoni). Sometimes when they want to test something with a new approach, they send the samples to higher-level research institutions (ex: to LUMC for the new testing of CAA). (POC (CCA) is implemented in the field already.)
It is not important for us "where" it is tested.
A wide arrange of people are capable to do the diagnostic.
V Data and time of diagnostic
The date and time are important but a lot of time it is not reported.
V Amount of urine per sample
The amount of urine used (per sample) is important and it is reported.

V Occult blood of urine
Occult blood of urine is important.
V Yeast / Fungus / Parasite

-INPUT-
V Dynamic Data
Dynamic data, and with the same frequency as "the infected area data" (comes together). It can less than once a year to know regional level data (ex: how many people are there in the infected area)
V Less than a year (preferably repeated)
Repeated test on the same participants can be useful.
Having repeated sample per individuals, keeping the same condition. -- The accuracy level of infection in the given individual -- when the diagnostic is given only depending on one sample, it is hard to know the liability.
(For many years, it has been done for Schistosoma mansoni, as there are many factors that can influence the presence of eggs, so they will have individuals testing in a different setting)
To understand the prediction of the scenario, the more the better picture you get.
The repeated process is also depending on how expensive the diagnostic process, as well as the logistics of the diagnostic.
It is more important to know day to day variety, instead of before or after treatment. (←different purpose)
Currently, it is often a random sample of the population that is being collected, which is also good and bad. For the collaboration that we are soon doing with Glasgow, it will be on the same individual over the different round of MDA.



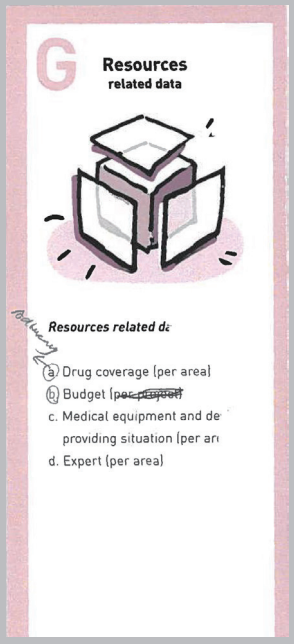


F. Parasite related data -- both as an input and output, but on a different level. It is used for 1. further understand the disease situation, and 2. Predict the future.
Parasite related data can be both input and output, but on a different level.
FOI (force of infection) is in between input and output, it is an assumption we make, and value made to assume number we don't know. Based on the result calculated from the FOI, conclusions can be made. FOI is not possible to get from the field, it is not data. It can be an input we have in modeling.
V Parasite prevalence
Parasite prevalence can be something we measure straight away from the field as input and something we generate as an output.
We do a model that tries to understand why you understand this parasite prevalence in the past year, and what parasite prevalence you might have in the future. (the number of people positive (lightly + moderate + heavy infected)/ number of people tested %)

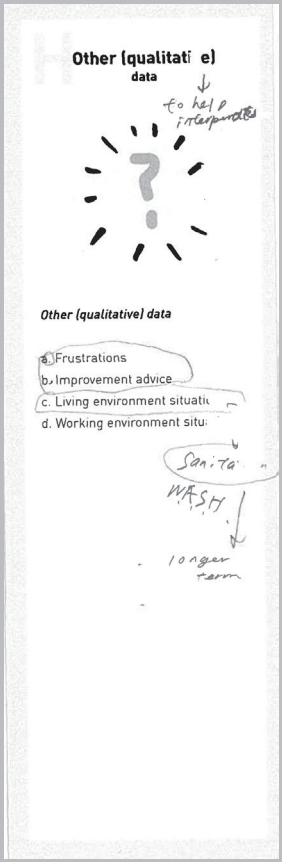
We can generate it more into detail from the parasite prevalence.
V Infectious intensity
Lightly, moderate, heavy infected is depending on the number of eggs per gram →→ data of "infectious intensity"
V Parasite taxon
V Parasite-host species
V Parasite antigens
(As mentioned in the future collaboration plan with LUMC) CAA can be both input and output but on a different level.

-INPUT-
V Dynamic Data V Static Data
Both primary and secondary. The accuracy is really important in this group of data. It is important that the data is collected.
V Annually (but preferred to be more frequently)
The more often the better. It is now around once a year. The frequency of the output is really projected specific. In terms of a conference or a report, it is mostly annually.

-OUTPUT-
V Annually
V Report/ Paper / Conference
The result is mostly published as a scientific paper. The first level of exposure is of course research institutions (local and international), generating scientific discussion, but not government level in the beginning. The output doesn't all the time reach the local government or WHO. If the result is considered relevant for the WHO, they will take into consideration and discuss it. By then, the ideal situation is to get the influence back to the local field.
Discussing the published papers is even better to been discussed at a conference, then the exposure is more possible to reach into a different field (manager, technicians...).
For WHO, our output doesn't always reach it every year. For example, the 2020 goal and guideline for control of disease, and 2030 is coming after... it is not by year.



G. Resource related data -- not from a country perspective, but from the point of view of how resources can influence the research.
V Drug coverage (see Data C: Adherence)
V Budget (related to the cost of approach)
Budget is not necessary on a project level. It is relevant to the cost-effectiveness to evaluate a new intervention, or an introduction of a new diagnostic -- "how much are you willing to pay for this? "
The cost of diagnostic can influence the implementation of an approach. (see Q8, the issue for applying the expensive CAA)



H. Other qualitative data -- help interpret results
It may help understand why things went wrong if it doesn't go as planned.
If you have only partial data of what is needed, it is possible that you will have to make an assumption for the lacking data, in order to produce modeling and prediction.
V Frustrations
V Improvement advice
If the output result doesn't show affirmative, it could be that there is something wrong in the field. Knowing "frustrations, improvements advice, ..." these qualitative data may help interpretation result. Ex: issue with the logistics, people are not skillful enough in analyzing, or the interpretation of guidelines is not done correctly by the country.
V Living environment situation
The living condition can be also helpful in trying to understand what is happening in the field. Schisto is so much related to poverty. If people don't have the place to help break the transmission cycle, even if you continue to do MDA, it will not work.

Q10. If anything is possible in terms of technology, what would you like to see happening?
A10. The more accurate the better, for example being able to detect light infection. Maybe it is not possible to be achieved only by technology, but together with a scientific point of view. The cost can also be a limitation. It is budget-wise better to treat everyone instead of test everyone. It is not currently a big argument (not really a side effect) to give everyone drug even though they are not ill with Schisto. But in some settings, the intensity is really low, then it is not cost-efficient to treat everyone, but just to test. If it is a few people infected, then the technology accuracy in detecting light infection will be important.
For infection intensity, low limit detecting is a threshold. How low should the limit detection (N-/N+) be in order to be able to say the elimination is achieved. On a population level (instead of individual) it is possible to say " it is not going to be transmission anymore". Because of this low detection limit, you will always have some people who missed, but it is not always important, as the infected population is so low that it is not going to make the transmission, and will fade away, as the cycle is broken.

Q11. What is your suggestion to ultimately eliminate Schistosomiasis?
A11. Medication, infrastructure, and economy influence each other.
The intervention of WASH should be happening together with MDA. The fact of improving sanitation and hygiene is in a much longer-term. If the condition can be improved, people have to accept it and get the meaning of it, they have to maintain it (not just about having an NGO to donate facilities)
To solve the ultimate problem. if there is unlimited money, the money should not be used on MDA but improving the facilities. But this is a long term issue -- people have to accept is and make a change in their habit. Improving the economic situation can also help maintain, as it will not have to be done by outsiders.

C.b.d KEMRI (Kenya Medical Research Institute)

KEMRI's main job is: to monitor the impact of MDA. School-based, what is the impact of the drugs on the children? Is it going as expected? Is there any other thing happening?
We are currently dealing with :
1. STH (Soil-transmitted helminths) ("helminth" means parasitic worm): Ascaris lumbricoides (sometimes called just "Ascaris"), whipworm (Trichuris trichiura), and hookworm (Ancylostoma duodenale and Necator americanus)
2. Schistosomiasis
Schistosoma haematobium -- at the coastal area + lake region
schistosomiasis mansoni -- middle part of Kenya + lake region

The procedure is now taking 2012-2017 → most project is taking 5 years. 5 years is depending on 1. Financial issue 2. The most project has a lifespan of 5 years.
After 5 years, we sit down and make iteration on how we need to progress and how we should adjust.
We sit down as a country of Kenya, as the "Steering committee". We have to sit down and discuss:
1. What did we achieve in 5 years?
2. How did we do it?
3. What did we exclude that we need to include?
4. How are we able to sustain?
(as these 5 years is mainly foreign support, we get drugs for free/ and the biggest finance we get it from CIFF-, based in UK/ Government provides personnel, venue, area,...)

This stirring committee is for many problems. CIFF has it stated clearly: within 5 years, you have to come up with a sustainability plan, how do you go on in achieving the goal of eliminating the disease.
For diagnostic:
Schistosoma haematobium -- filtration (not dipstick)
Schistosomiasis mansoni -- kato katz

The new diagnostic device is very important, and being affordable is very important.
The current problem in diagnostic is light-infection.
CWW (children without worms) - meeting in America, Switzerland, Belgium

"The biggest concern is the accuracy of the method we are using for Schistosomiasis."

We are all in agreement. We know that Kato Kotz is very difficult to detect light infection. The ideal new method that can be a really big breakthrough, should be affordable and user-friendly.

The new diagnostic method that is currently about to test: Helmintex Method

	Year 1	Year 2	Year 3	Year 4	Year 5	(Explain)
Situation 1	MDA + Survey	MDA	MDA + Survey	MDA	MDA + Survey	Support 200 school county wise, out of the four regions (Provence as a unit. Ex: western province (around the lake)/ Nyanza province(around the lake)/ Rift valley/coast) The affordable solution for the government. → the sustainable solution for now.
Situation 2	MDA + Survey	MDA + Survey	MDA + Survey	MDA + Survey	MDA + Survey	Out of the 200 schools, we choose 60 schools to do every year Downside: monitoring every year is too much. As the result won't change (in the middle of the whole process), and the money is only spent to see small numbers dropping..., the change is not fast, so no need to survey test every year. One of the main purposes: to report the coverage data to WHO

economical concern: the more frequent you do it, the more expensive it will be
Different voice of not testing every year (from other partners):
"Doing it every year? No! You are overdoing it! What is important is before and after. If the drug is working anyway, there will eventually be some decline. " -- partner anonymous

Collection of data is done through two sets of people:
1. People from research institution (KEMRI) → planning from Nairobi
2. People from local county government (ministry of health, director of health, laboratory personnel, country laboratory technologist in charge of the lab...) → people in touch with the local citizen

Collaboration between KEMRI and local gov. The steering committee can be seen as the government. Structure from KENYA national school health policy, since 2009

West African region	East African region	Asian region
Ghana - NMIMR (Noguchi Memorial Institute for Medical Research)	Kenya - KEMRI (Kenya Medical Research Institute) Countries under: Kenya Ethiopia Uganda Tanzania Zambia Zimbabwe Malawi Botswana	Thailand - (MU) Mahidol University

Stakeholder		Task
Local research institution	KEMRI	Look for funds, to continue for the 6th year of elimination (after the round of 5 years)
Ministry of health	Director of medical service	Chair of the committee Inform the government, inform the ministry Make the call in action
	NTD committee	Acquisition of drugs that come through WHO to the government. Discuss with WHO
Ministry of Education	Director of education	Chair of the committee (Since it is deworming on children, need permission to go to schools)
Local WHO	(representative)	
Local NGO	Evidence Action	On behalf of the ministry of health. Schedule the program (when to do what) Look for funds, to continue for the 6th year of elimination (after the round of 5 years)

Kenya is the first that came with the school health policy.
Kenya National School-Based Deworming Programme (NSBDP):
Schistosomiasis/STH/Lymphatic Filariasis/Malaria
Each country has its own structure (financial, partners,...), but share the same goal: to eliminate the disease.Ex:
1. Kenya → school-based → supported by JICA, help training
(JICA is not involved in national control, but in coordinated for parasite control in the region, pilot study + field site for training purpose in Kenya)
2. Uganda → school-based + community-based → supported by SCI (Schistosomiasis Control Initiative)
3. Zambia → supported by USAID

- Pass health-related message: Community health workers are used to pass a health-related message to the field.
- Survey test + MDA: KEMRI + (medical people, Level 2,3 hospital) technicians, laboratory people in the county. (Sample diagnostic in the county laboratory (hospital). Using the space in a local laboratory for diagnostic.)

People do not go to the hospital, unless they see the symptoms (normally for haematobium in urine), or unless in the later stage of a chronic stage.
(unless they are aware of continued blood in urine, some don't even think blood in urine is a problem) (Schistosomiasis mansoni, no one goes to the hospital themselves)

Meetings at the county level invite the following:
[community sensitization]: the community has the right to know everything

Chief assistance	security	In charge of security of the survey & MDA process Know why you are moving around, asking questions....
Local administration		
Community health workers	trust	The people in touch with the citizen on a root level Build trust between survey & MDA team and citizen
Community health volunteers		

The main exercise of KEMRI: to monitor the impact of MDA.
Second goal: Education. help student derived proposal and supervise them: a Master student from university working on BCC (behavior change and communication)
Ex: is there resistance in the drugs after so many years? What is the difference between certain areas? The drug's effects on Maasai people, as they move around? What is the egg reduction rate? Cure rate? ...comparing between different method?
Students come up with the survey and diagnostic method to join the team in the field (for testing). This is the side project for KEMRI
The new diagnostic method has to go through the KEMRI review process: Present →→ receive comments → to Ethical & Scientific review.
1. Ethical: you don't dehumanize, don't jeopardize people you do samples for. The data has to be acceptable. → Worldwide guideline: confidentiality ensuring, no commercial advantage, guardian signing agreement forms for permission, free willing to be tested...
2. Scientific: is the method feasible, is there clear operation procedure clear, is the objective clear, what is the goal to achieve, how will it be beneficial to the citizen, what questions do you want to answer....

WHO consume the result, the country gets the donated drugs.
Donated drugs come through :
International pharmaceutical companies → WHO → country
The data report to WHO yearly:
Is it creating an impact? Is the worm infection going down? What is the coverage? 6000000 doses of drugs were given to 6000000 children, and what is the coverage? Is all of them getting the drugs?
Report goal is to show: the drug is working, as the infection rate is declining.
Statistical samples are taken from the same school (school as a unit), only a few children can be truly monitored on an individual level.

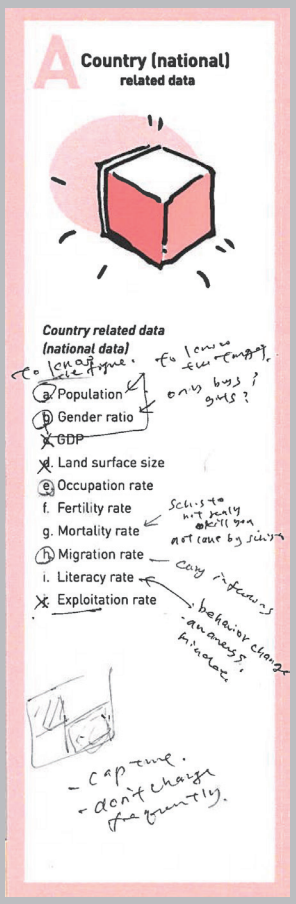
MDA and ME are described as "sleeping in the same bed while having different dreams":

The sustainable solution that can go on forever, is ME.
Still doing MDA when the prevalence low is a waste.
When you are reaching elimination, the system should switch to ME.

		explain	Arguments/drawbacks	A possible solution to combine both approach
WHO style guideline	MDA → Mass drug administration Mass treatment Partly examine	Treat everybody, examine only a sample. You examine 200 children. 6000000 children at risk? You treat 6000000 children.	From WHO, each country does the same, MDA is the best way to compare the results. However, Some treated people were never even tested, they don't think they have worms, so they don't want and don't understand why they should take the drug. Untaken drugs can always be found in the pits because people don't know why should they take the drug.	If the disease prevalence is high (→50%), do MDA. If the disease prevalence is low (←20%), do ME, as doing MDA can be meaningless, it is just wasting drugs. ME is successfully done in Japan. The whole idea: "There is no diagnostic you get it for free... but we made it very cheap" ... Children are asked to put their stool in a matching box plus an additional 20 shillings (= around 0.2 euro). Training people to become microscopist is not difficult. 20 shillings a processing of a sample, 30 sample processing a day for one microscopist. If the whole sample processing takes 10 days, for one round of survey, one microscopist gets 6000 shillings for 10 days. If you are tested positive, you go to the health center, then you are treated.
Japanese style guideline	ME → Mass examination Selective treatment	Examine everybody, treat only the positive. Test everybody. Those you find positive, you treat.	1. When you are treating all, and the prevalence is 20%, it means 80% of the drugs is wasted. 2. Treating only children who are positive, can save unnecessary drugs, and put the saved money in the diagnostic. Educative approach, you have to always explain why when they are taking the treatment. People who are positive can even come and take a look at the eggs under the microscope. People who had it positive will also be curious to know if they have it next year after treatment, which indicates the increasing of awareness. If the prevalence is low, then doing MDA is just wasting drugs. Because the drugs are freely donated, so countries don't mind wasting the drug. If countries have to pay for the drugs, MDA will not be used, and they will find their way in treatment and find out who is positive. If someone tells you now that you have hookworm, you will go to every chemist until you find a drug for treatment. When you really understand that you have the disease by seeing it and knowing it, you will definitely look for treatment no matter what, and you will pay for it if it has to be.	

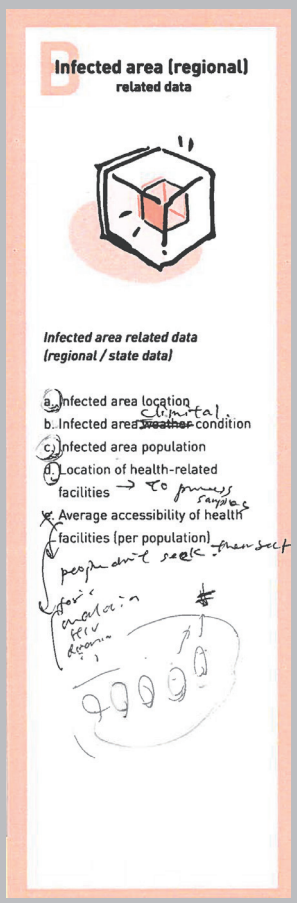
Other methods:
Making rivers into channels, making snails not able to survive, but harm the ecosystem
Mostly the result of MDA as output. The purpose of collaborating with an international agency is clear: parasite control coordination in the region

Collaborate with many international parties but on a certain specific area of interest.
Most doner and financial are external.



A. Country related data - don't change often.

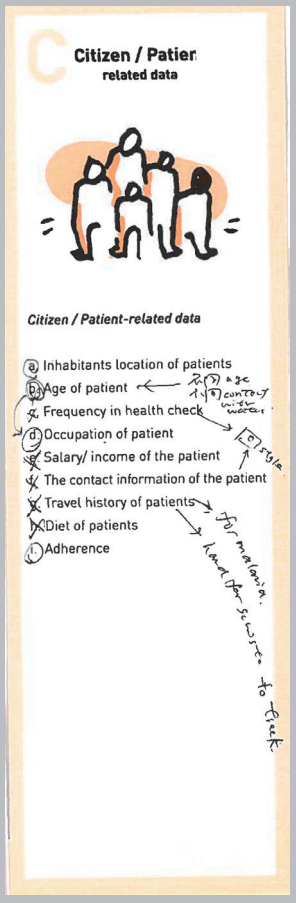
V Population rate
To know the target population. How many are you going to survey? It is necessary to know to have an estimation for the planning for the test.
V Gender ratio
V Occupation rate
X Mortality rate
It is hard to hear something like " this year, xxx people died of schistosomiasis" →→ NTD, you are hard to die from only it
V Migration rate
V Literacy rate
Especially the behavior, mindset, and awareness is being researched
X Exploitation rate
Too far fetch


B
Infected area (regional)
related data
Infected area related data
(regional / state data)
a. Infected area location
b. Infected area weather condition
c. Infected area population
d. Location of health-related facilities
e. Average accessibility of health facilities (per population)

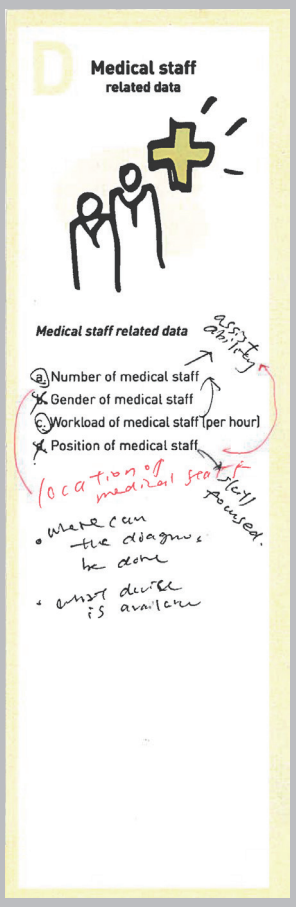
B. Infected area related data

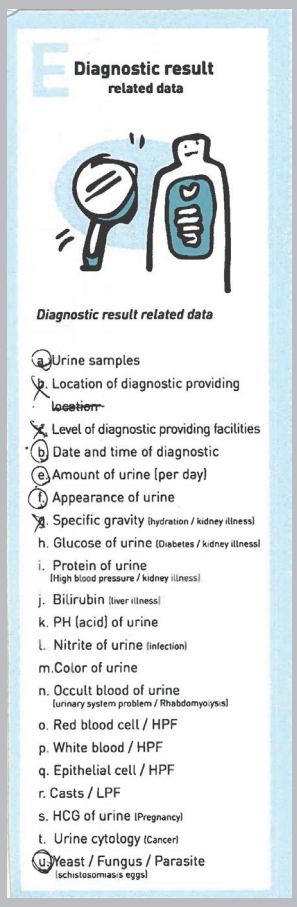
V Infected area location
V Infected area climatic condition
More climatic condition (instead of weather) Someplace is safe from Schistosomiasis because it is very dry.
V Infected area population
Before doing the survey, want to know approximately the amount
V Location of health-related facilities
To do process the samples. To know where are all the labs, which are able to process the samples
X Average accessibility
Not directly. People nearly never seek medication, even though we hope they do it. Hard for people to know.
Health seeking behavior of the behavior is determined by other diseases (ex: malaria.)
Schistosomiasis will not bring people down immediately

C. Citizen / Patient-related data



V Inhabitants location
How people are related to the water
V Age
Children are often more accessible to water. Different age group have different accessibility rate to water
X Frequency in a health check
MDA doesn't matter. ME matters
V Occupation
Different occupations have different accessibility rate to water.
X Salary / income
People don't pay for the drug
X Contact information
MDA doesn't matter. ME matters as you have to trace them and inform them,
X Travel history
The history of traveling is more for the disease that shows symptoms immediately, for example, Malaria.
For schistosomiasis, it can take a very long period of time (e.g. 2 years) before the symptoms are shown. Not really worth tracing.
X Diet of patients
V Adherence
Drug adherence, yes. Whether they did take the drugs or not.



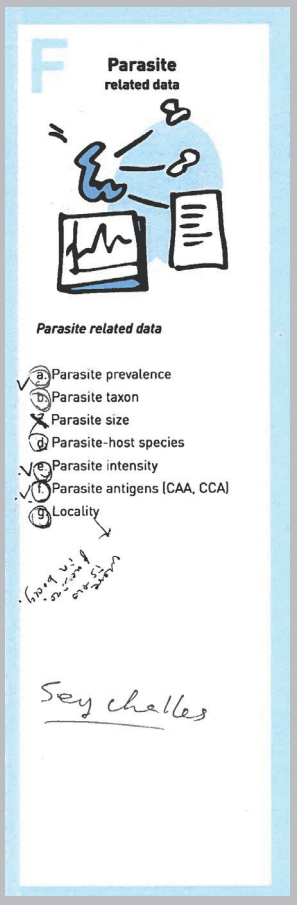

E
Diagnostic result
related data
Diagnostic result related data
a Urine samples
b. Location of diagnostic providing
Level of diagnostic providing facilities
d Date and time of diagnostic
e Amount of urine (per day)
f Appearance of urine
g. Specific gravity (hydration / kidney illness)
h. Glucose of urine (Diabetes / kidney illness)
i. Protein of urine (High blood pressure / kidney illness)
j. Bilirubin (liver illness)
k. PH (acid) of urine
l. Nitrite of urine (infection)
m. Color of urine
n. Occult blood of urine (urinary system problem / Rhabdomyolysis)
o. Red blood cell / HPF
p. White blood / HPF
q. Epithelial cell / HPF
r. Casts / LPF
s. HCG of urine (Pregnancy)
t. Urine cytology (Cancer)
u Yeast / Fungus / Parasite (schistosomiasis eggs)

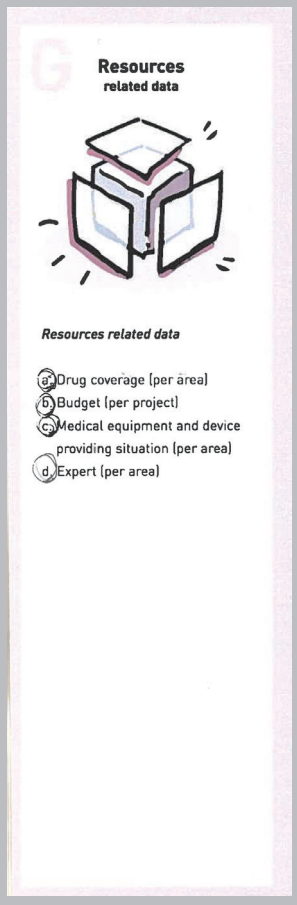
D. Medical staff-related data -- mainly to know the availability of assistance, what facilities are able to do the job.

V Number of medical staff
To know the availability of assistance
V Location of medical staff
To know the availability of assistance
V The workload of medical staff
Related with the availability of assistance
X Position of staff
Skills focused, instead of position

E. Diagnostic result related data

V Urine samples
X Location of diagnostic
No. It is about the proximate "Where can the examination be done, what equipment and facility are available". where it is diagnosed is not important. We will also not carry the sample to KEMRI at Nairobi. We do the



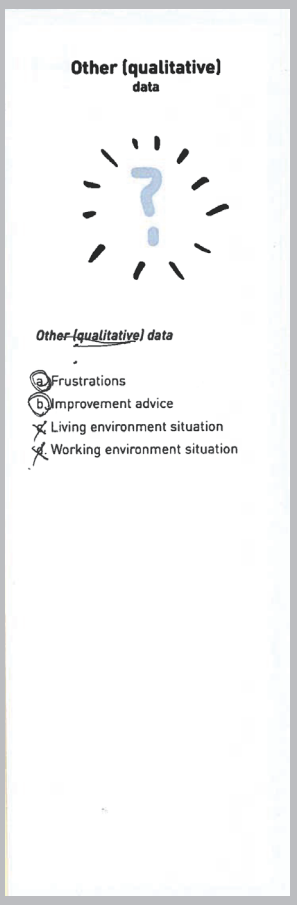


F. Parasite related data

V Parasite prevalence (One of the most important)
V Parasite taxon
V Parasite-host species
V Parasite intensity (On e of the most important) will infect the prevalence
V Parasite antigens (One of the most important) depend on the method (CAA CCA)
V Locality
Important to know where it is found, as schistosomiasis is really a location effective.

G. Resources related data

V Drug coverage
V Budget
V Equipment and device
V Expert
Expert is needed to arrange the controlling program

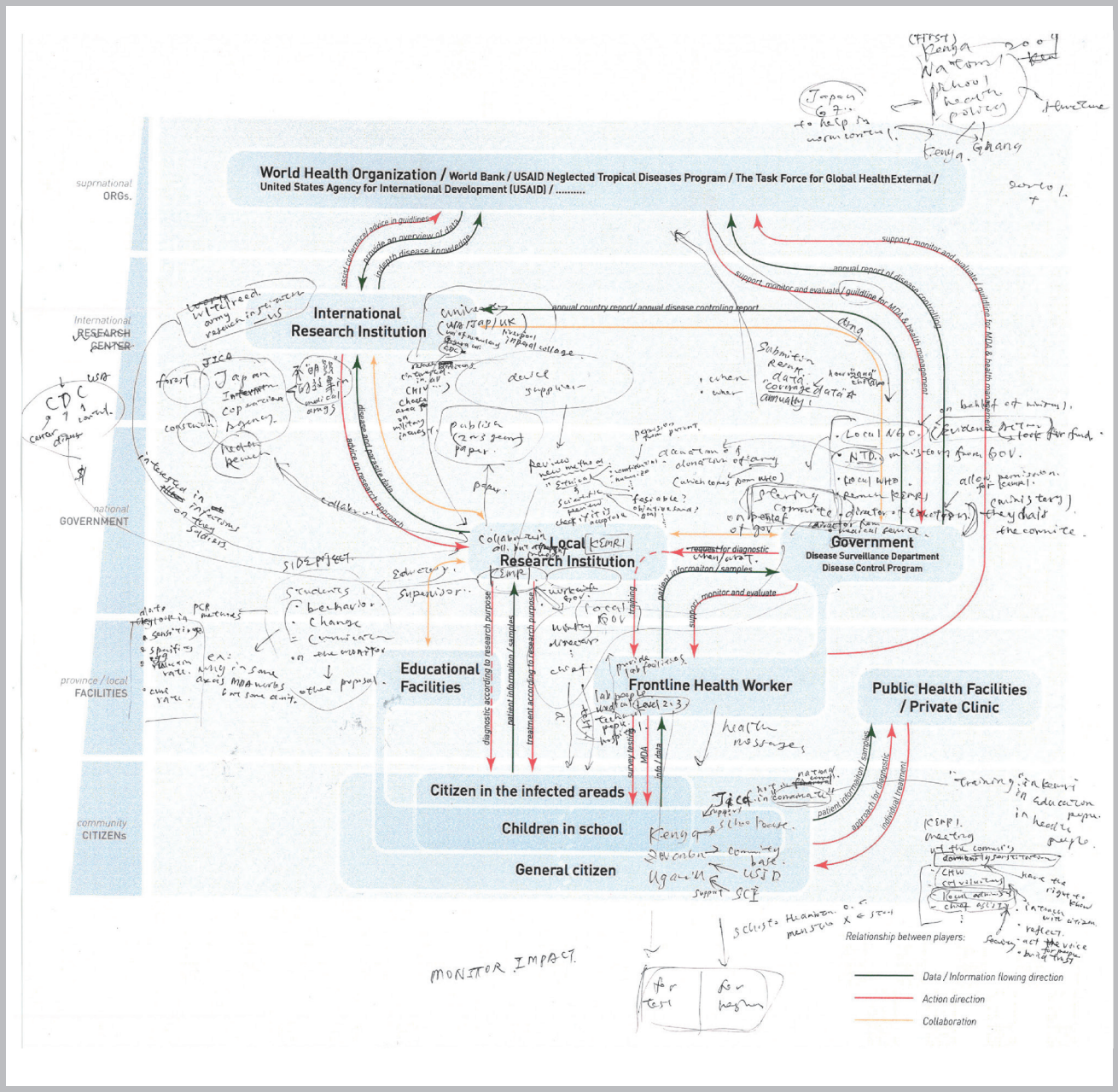


H. Other

V Frustrations
V Improvement advice
X Living situation Doesn't matter much

The ideal diagnostic device should have these two key elements to be applicable to the field:
1) Sensitivity. The better the better
It should be sensitive and can be used in extreme circumstances, and to know if the parasite has been successfully eliminated.
2) User-friendly in the field
The benefit of Kato Kaze is that it can be done even in a classroom. It has to be a method that we can be done with "mass" diagnostic. PCR is only able to be in a certain lab, so it is not user-friendly.
3) Affordable
It cannot be very expensive beyond research.

→ it is hard to have it all: be sensitive, user-friendly and at the same time affordable to be in order applicable.
The main problem is about light infection -- sensitive. The


World Health Organization / World Bank / USAID Neglected Tropical Diseases Program / The Task Force for Global HealthExternal / United States Agency for International Development (USAID) / .....
supranational ORGs.
International RESEARCH CENTER
national GOVERNMENT
province / local FACILITIES
community CITIZENs
International Research Institution
Local Research Institution
Government
Disease Surveillance Department
Disease Control Program
Educational Facilities
Frontline Health Worker
Public Health Facilities / Private Clinic
Citizen in the infected areads
Children in school
General citizen
MONITOR IMPACT
Relationship between players:
Data / Information flowing direction
Action direction
Collaboration

device loses its sensitivity.
If there is also a way to make Kato Kaze less smelly and chemical some, it will be good. The whole world is looking for techniques to look for sensitive to detect light infection, and not miss the eggs in the sample. If bureaucracy can be avoided, things could be faster. But it can only be possible if the country is in charge of everything, instead of relying on the supply or sponsor from someone.

A good example of playing solo in deworming policy: country Seychelles.
The buy their own drugs, and they deworm school children three times a year. The moment the semester starts, drugs are ready, and the children take it. If a country has the control, and budget for the activities, there is no reliance on donor funding, (drugs, and diagnostic)

Japanese style in facing Schistosomiasis
As long as you are waiting for the drugs to come, you are also waiting for the money to come and bring the drugs to the school, you will also have to wait for CIFF ..., by the time

you get to bring the drugs to the kids, a lot of time is wasted. Many times the drugs are just there in the airport customs waiting because there is too much bureaucracy. Developing is not on the process and arranged by the government. If the drugs are ordered by the government, all the process can be much faster, no one will be asking much about why do you need the drug, who is in charge, what is it for, where will it go to...

Main Data flow:
The government is now not taking control. We all send our data to the government and tell WHO how much drug we need. At the same time WHO ask for the impact, we've created out from the drugs given to us. We are now doing it once a year. But if our government is doing it, we will be able to do it twice or three times a year.

C.b.e Akvo

Q1. How Akvo sees the biggest problem in adapting data usage.
A1. How they can use data fn our (mobile data collected) tools, we don't have a way to share data back to or internal learning and feedback the data you collect back to the community. Ithe beneficiary. We will have to completely change our software structure, to be able to give advice to those who we have been collecting data from, or something that can assist data collector to give advice on the spot.

Q2. What is Akvo's position currently?
A2. Sometimes Akvo is in the consortium, sometimes we are outside of it. Usually, organizations decide what they want (want to be countable, want to quantify result, want to know if the intervention is working). They have their own monitoring evaluation process worked out themselves.
Akvo 1. provides the tool to help collect the data they needed. Akvo 2. trains people to use the tool (which can help them collect the data.) 3. Build on the capacity of moving people from paperwork to digital, help them shift away from the old way of collecting data (advance survey with skip logic, with pictures, with GPS locations...)

Q3. How do people know they have to approach Akvo and seeks for help: (when do people start to be aware that the data they need is not enough):
A3. 1) Sometimes it is pushed by donner→ external pressure due to expectations
2) Hard to conclude when a project ends → lacking data to show progress
→ it is often Akvo comes in late, people often think of Akvo when they really need the help of Akvo in extracting digital data.

Partners are gradually getting used to this monitor & evaluation process of data, so they come to Akvo earlier. Akvo not only help in designing tools (for data collections) but help in

designing the design process (facilitate internal parties knowing what goal are they aiming for)

◦ Problems Akvo see:
→ They don't have the right data to show what they aim to show. (→→ the approach and goal is not aligned), with the wrong approach, the wrong survey...
→ Partners often find it difficult to translate what they want into a Monitoring framework
→ hard to identify the indicators to carry out the result.

Thus:
→ Akvo try to conceptualize the way people work and make it a journey. A project managing, while targeting towards data collection phase.
→ try to start at the earlier phase when every stakeholder is all presented
Help define the ultimate goal, structure the intermediate goals.
→ Aiming to help align thinking of the partners. (which also assist Akvo in understanding what they want to get as the end result.)

◦ Akvo's goal:
Want a more sustainable and effective and inclusive governs, in developing countries.
Via organizations that work in the development sector more effective in their work via data, and the way they work with data.
→ help organizations to maximize the outcome of their resources via the right approach to efficiently collect data. (The goal can be slightly different)

Q4. How is Akvo related to health issues?
A4. Akvo has projects that focus a lot on water quality, "Is it safe drinking water?"
Try to integrate the system in DHIS2 (District Health Information System 2 (DHIS2)
DHIS2: a health database that is widely used in developing countries.
DHIS2 have their own data collecting application, but Akvo also has it. We try to (advocate our partners too) contribute to the database.
We try to make the data we collect directly into open data platforms such as DHIS2.
Akvo has our data collection, and we'd like to contribute to DHIS2 this database

Q5. How do you deal with ethical, privacy, and ownership related concerns in health data.
A5. The Akvo system is secure, the engagements with DHIS2 is also secure. The concern is there, that's why we have GDPR. Also, Akvo doesn't own the data, so Akvo doesn't own the data. We are here to increase the connection between the data and the client. Data itself has not much value for Akvo.

Q6. How can the world of data usage better improve?
A6. We all want data help inefficiency, thus we want to open a portal, to avoid data silo. People sometimes go to the same place, they do the same collection... it is just assumed that we don't have a national database that we can just find the latest information. Thus, we as Akvo tries to advocate partners to open up their data.
There are of course data that seems to be always available, such as a country's demographic. However, this kind of open data is still dependent on the government. Countries like Ethiopia, they are very close to country data, they are not open to collaborations and do not have the mindset of data using.

Q7. Aside from sensor capturing, what are the other ways Akvo collects data?
A7. On Akvo's platform, we share "success stories"-- this is another way qualitative information can be seen. Focus group discussion can be made here.

Q8. In what kind of format does Akvo present the result and format?
A8. One of them will be the tool that helps generate reports automatically. The tool also reports on progress. The data can be both quantitative (through sensors and tools) or qualitative (through the platform mentioned previously), However, qualitative data are not really the expertise of Akvo.

Q9. What will the long term solution be for data usage and data approach?
A9. It depends on the project of our client. We want to also help them design sampling strategy in collecting data. We are not only training people who collect the data but also training people to design a proper survey based on their needs. It will be a collaborative result. We pride ourself in "facilitation", help organizations understand the importance of understanding the way data works, and how to train your staff. Instead of making data usage a black box, and only tell them what to do, we try to make them understand the value, which is also out added value as Akvo.

Q10. What is the barrier to implementing the data-based approach?
A10. 1) Knowledge gap can be big. It is a conceptual matter when we discuss. They don't know what they don't know, which makes conveying the message and convince difficultly. Thus, we as Akvo try to make the message into a checkbox and help them step by step to understand. This issue is also related to internal steering. There are a lot of ideas related to "why", why do you do this, why do you collect it. Why do you want it this way...

2) Acceptance. It is a new way of working. It may not be that "new" as they already approach Akvo. However, after Akvo consults them, sometimes they still intentionally do things the old way. It may take longer for them to get in the flow. The more traditional the company or organization is, the harder it will be to reach high acceptance. The older generation can also be difficult to tackle.

3) Skeptical and trust. People may be skeptical about our cloud-based-server. Clients more or less mind the ownership of data, and they want it to be in their server in their office. It may be hard to react. For example with government, they prefer internal solution and their own storage. This phenomenon, however, may be in conflict with the ideal world of open source and data sharing.

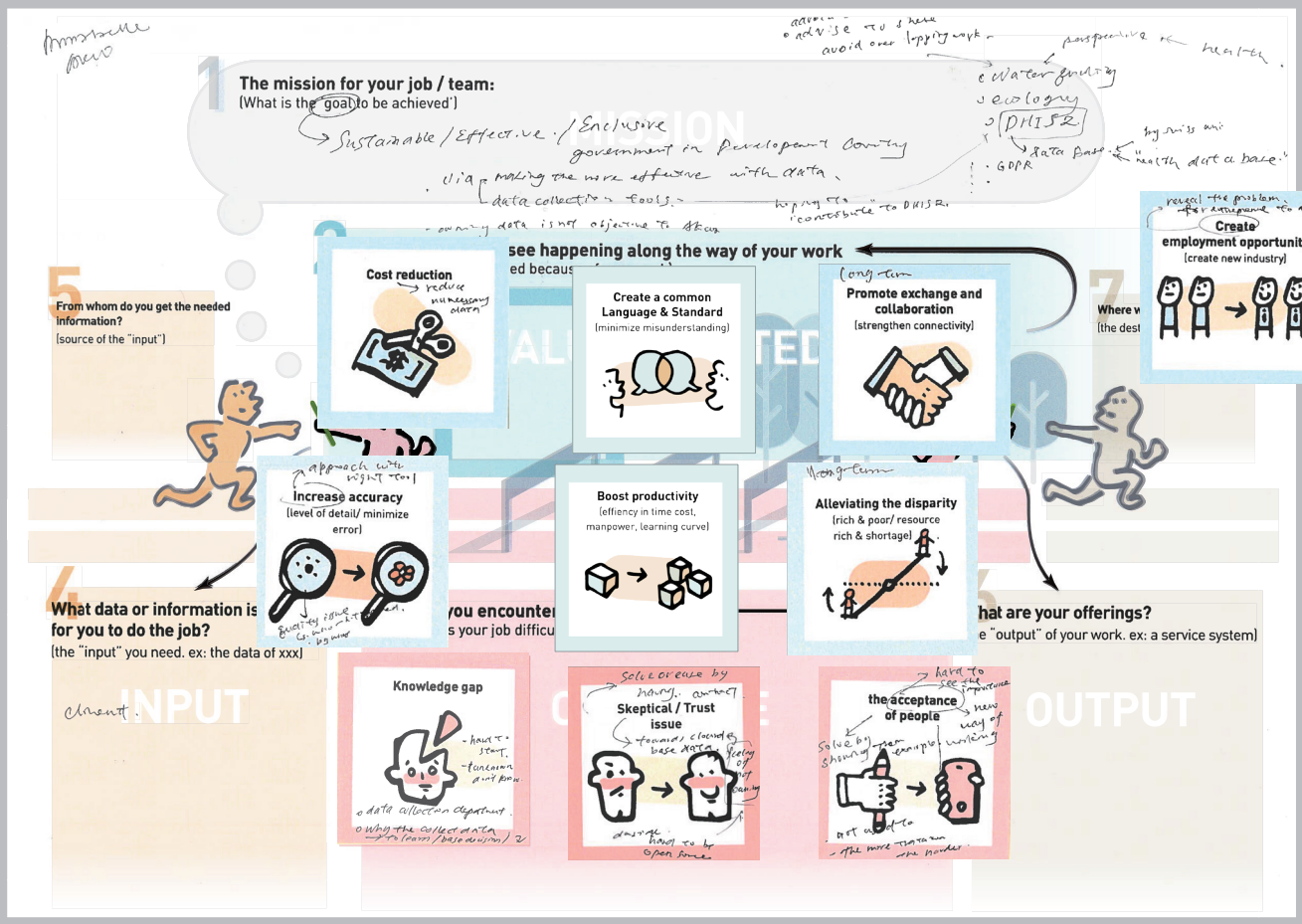
Q11. Do you ever encounter the problem of not having the right data to work on or the right information to process?
A11. Clients can have a very specific understanding of data collection. They might think the more data they collect, the better. This is also a bias.

Q12. Are governmental sectors slower and less efficient as a client as other organizations?
A12. Yes and no. The contacting process can always belong to every client. Larger NGOs can in a certain extent just like a government. There may be a lot of steps, which may be considered as bureaucratic. In that sense, private companies can be faster.

Q13. What is the added value you see happening because of your work?
The value can be long term and short term.
A13. 1) Reduce cost. In the process, we can reduce the cost because we know what and where to act, instead of wasting resources.

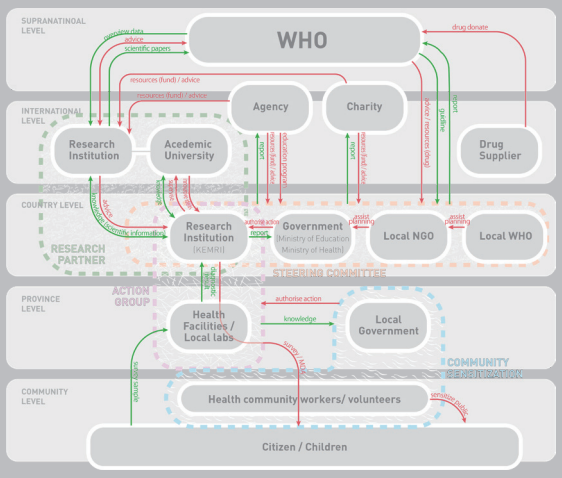
2) Increase accuracy. A lot of time data collectors don't have the proper way to collect data (ex: from whom, at which location), which sometimes result in the issue of quality. Through digitalization, we will be able to see the location they went to, and by this filter out insufficient data and chose not to work with certain data collectors or train them more.

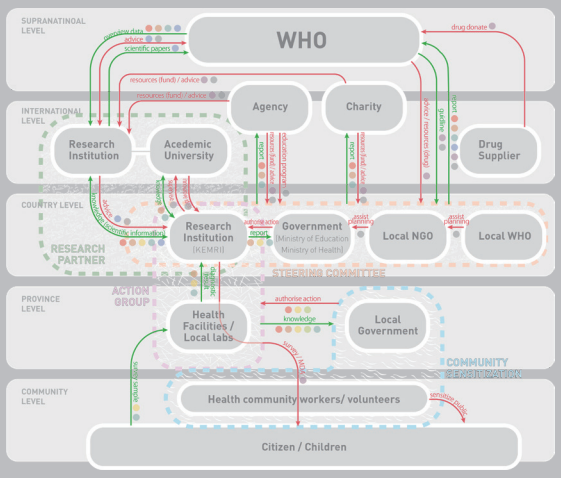
3) Depends on the project, something it can be private. It can be interesting for entrepreneurs will be able to log in on a platform and jump in to solve a problem. It may not be "open source", but the right collaboration can help open up opportunities for further problem-solving.


1
The mission for your job / team:
(What is the "goal" to be achieved")
Sustainable / Effective / Enclusive
government in Development Country
via making the more effective with data.
data collection tools
DHIS2
GDPR
see happening along the way of your work
Cost reduction
reduce unnecessary data
Create a common Language & Standard
(minimize misunderstanding)
Promote exchange and collaboration
(strengthen connectivity)
Create employment opportunity
(create new industry)
5
From whom do you get the needed information?
(source of the "input")
Increase accuracy
(level of detail/ minimize error)
Boost productivity
(effiency in time cost, manpower, learning curve)
Alleviating the disparity
(rich & poor/ resource rich & shortage)
4
What data or information is for you to do the job?
(the "input" you need. ex: the data of xxx)
Knowledge gap
Skeptical / Trust issue
the acceptance of people
INPUT
OUTPUT

D. The iteration of data flowing maps

Result: (see Figures 5-1, 5-2)

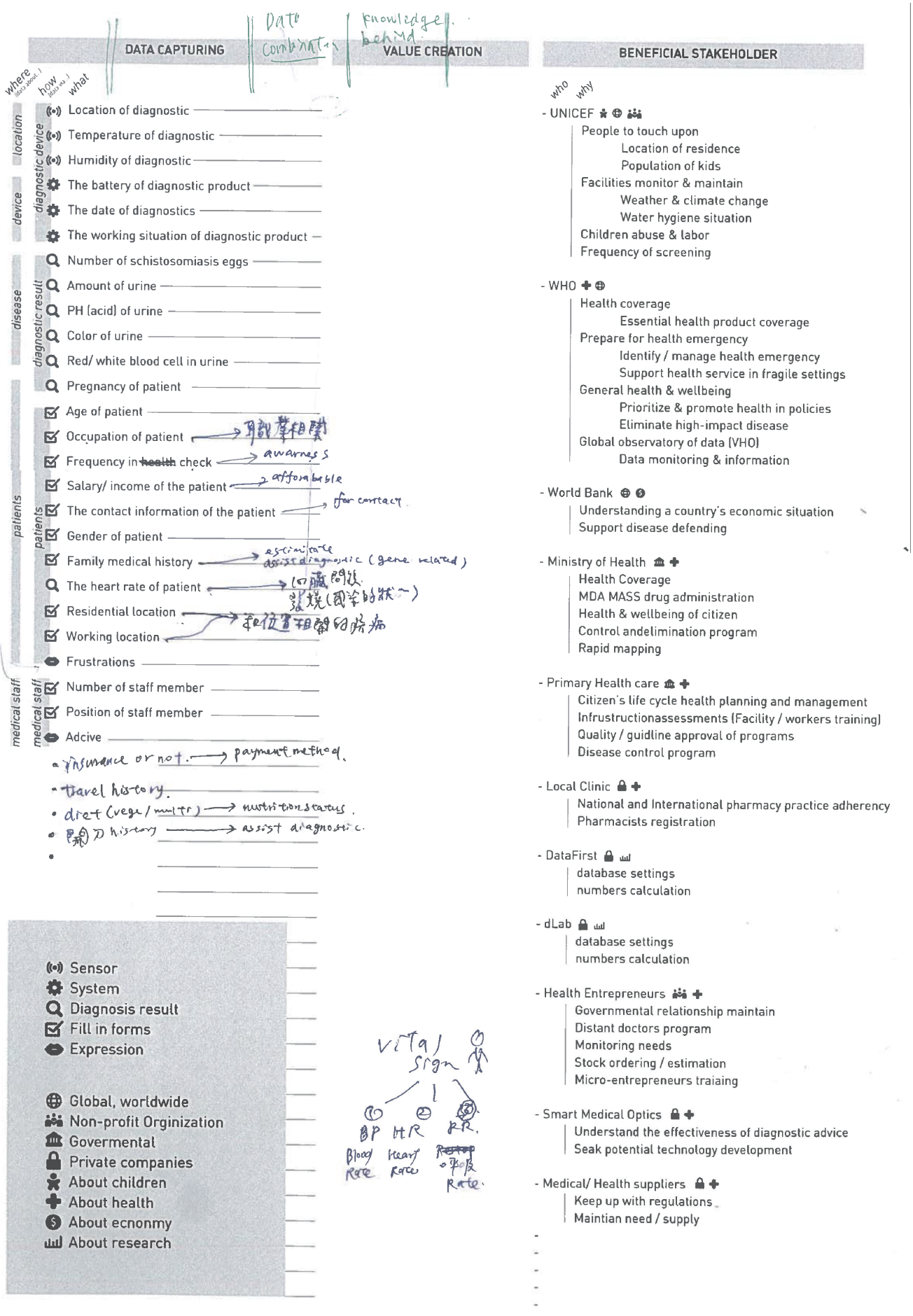


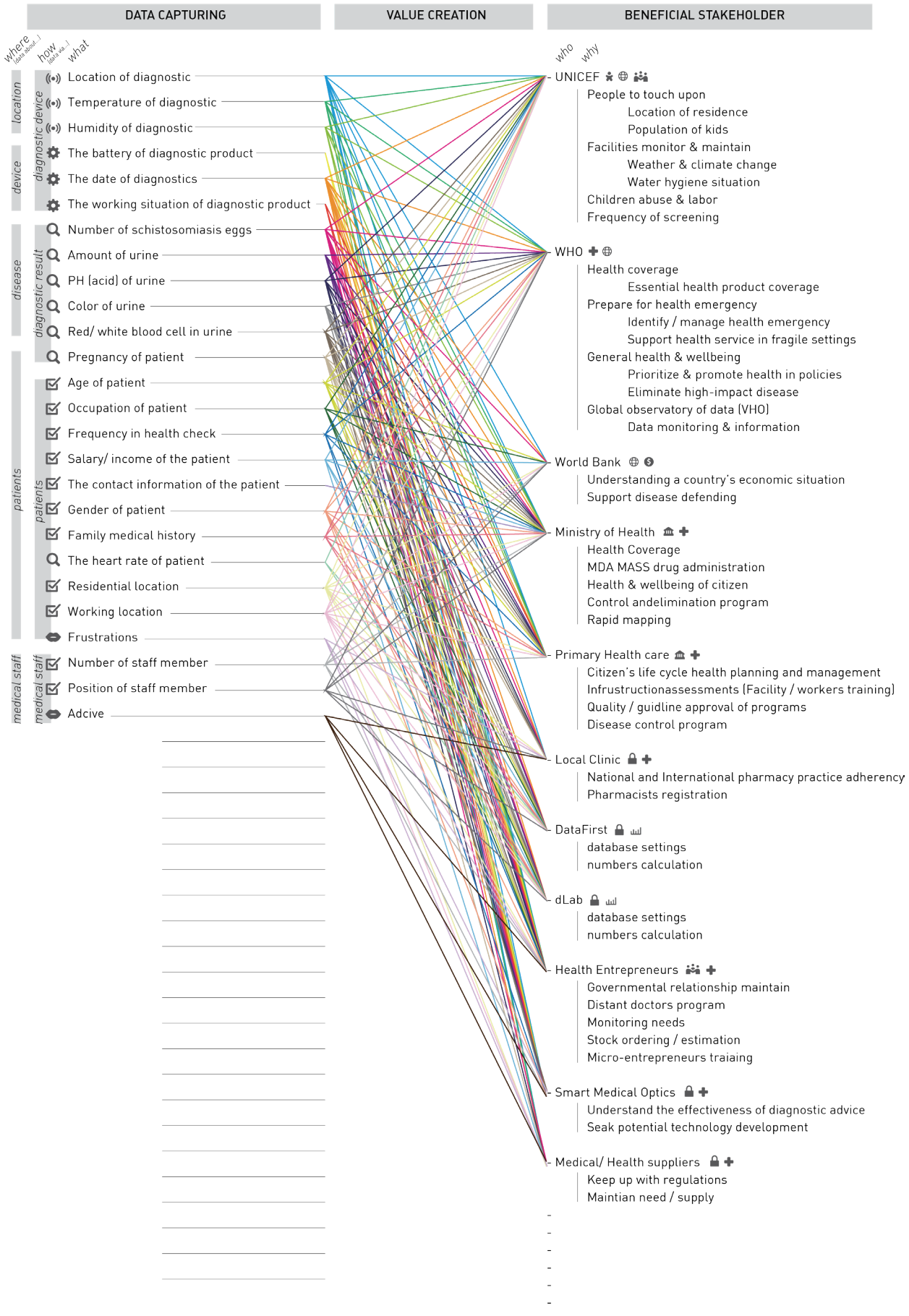


Progress:

	DATA CAPTURING (What data are there)					
	From/of who. (source).	When (frequency)	How (method)	Why (original purpose)	From ~~Who~~ / Where.	What (data)
1	location		sensor		device	location of diagnosis.
2	location		sensor.		device	temperature of diagnosis.
3	location		sensor		device	humidity of diagnosis.
4	product				device.	battery of device
5	product.				device.	in used or not (on or off).
6	product.				device.	if there is error
7	patient.			infected sch/to or not.	device(diagnosis) (result)	number of eggs.
8	patient			infection (general) or not.	device (diagnosis result)	ph (acid) of urine.
9	patient				device (diagnosis result)	color of urine
10	patient				device (diagnosis result)	crystal in urine or not.
11	patient					red blood cell
12	patient					white blood cell.
13	patient			document.	asking form fill	personal contact info.
14				document	asking form fill	age.
15				document.	ask/fill form	occupation.
16				document trace.	ask/fill form	frequency in health check
17				document trace	ask/fill form	(last time month checked)
18				being able to receive treatment or not.	ask/fill form	salary/income.
19				document	ask/fill device	pregency
20				document	ask/fill/observe	gender
21				document	ask/fill	family history.
22				document.	device	heart rate.
23				document.	device.	blood pressure.
24				document	ask/fill form	location of resident 居住位置.
25				document.	ask/fill form.	location of work. 工作位置.
26				document	ask/fill form	insurance.
27						
28						
29						
30						
31						
32						

	VALUE CREATION (who will find data interesting)				
Who	What (information)	Why (purpose of collection)	Where (operated location)	When (frequency of need)	reporting frequency
~~WHO~~ unicef	location of ~~pregnant~~ amount of population (kids)	map of people to touch upon			(city)
	education facilities ~~of~~				
wash	~~location~~ weather, climate change	maintain/monitor facilitation (toilets).			
unicef WASH project	water hygiene ~~sanitation~~	UNICEF WASH program. water sanitation and hygiene.			(city).
	frequency of monitor	kids abuse/ labor force			
who.	~~disease~~ health coverage	global observatory data (GHO). ensure essential health product			
		improve data monitoring and information.			
	prepare health emergency	identify & manage ~~risk~~ emergency			
		support health services in fragile settings.			
	health & wellbeing.	~~priority~~ prioritize ~~people~~ health in ~~at risk~~ populations			
		aim to the elimination and eradication of high impact disease.			
World Bank.	to decrease and understand country's economy status.	support in fighting NTDs.			
		to support eliminating ~~malaria~~ diseases.			
卫生部 Ministry of health					(region ~~age~~)
Datafirst.		database sorting			(research) in Africa
dLab.					(research center)
HE		to understand where are the people who are ~~at risk~~			
		distinguish remote community			
		potential area in-learning (HE).			
smart practical ~~application~~ app.		understand the effect of device.			(BV) 有人存钱
local clinic					
primary health care.					

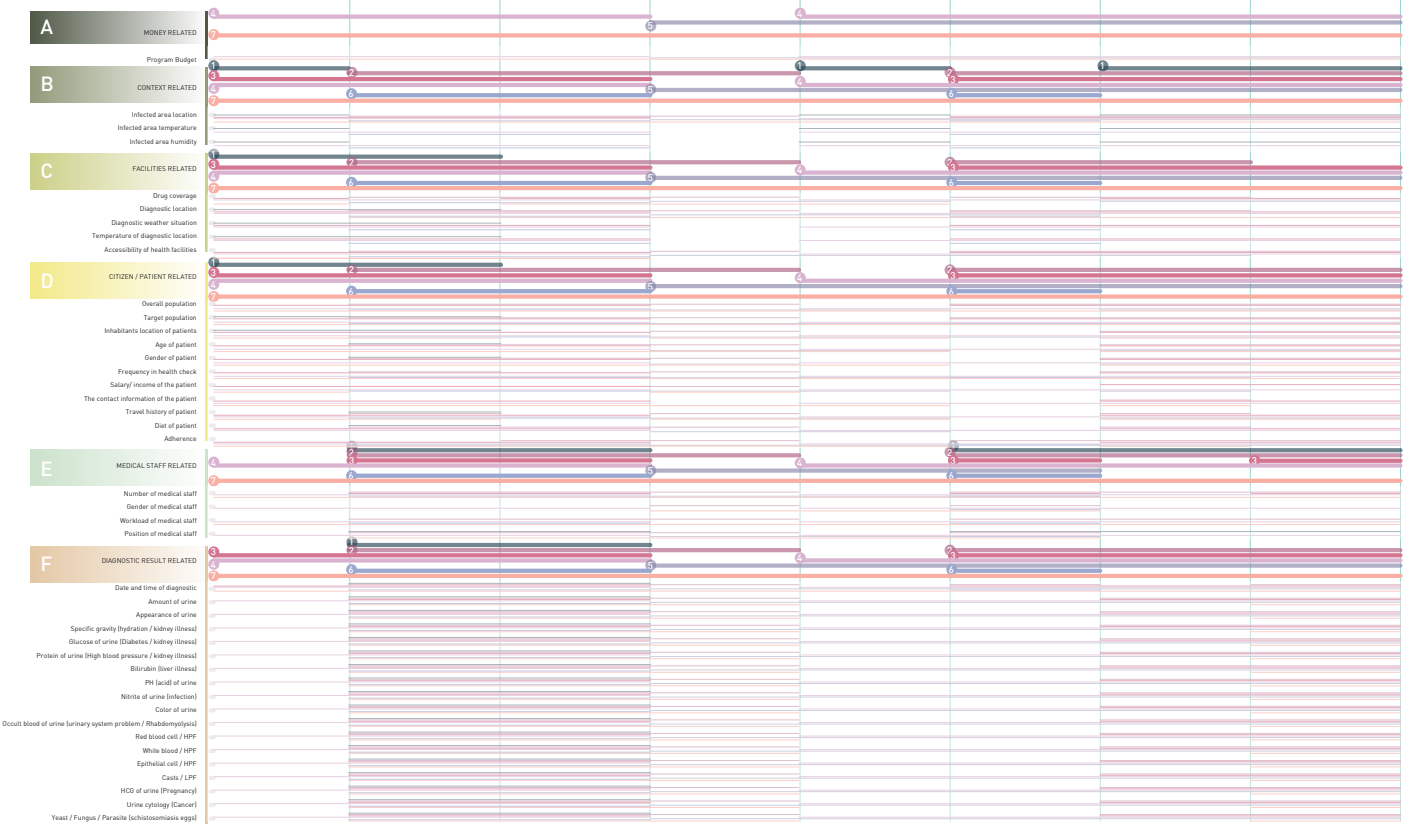

DATA CAPTURING
Data combination
knowledge behind
VALUE CREATION
BENEFICIAL STAKEHOLDER
where
how
what
location
device
diagnostic device
disease
diagnostic result
patients
medical staff
Location of diagnostic
Temperature of diagnostic
Humidity of diagnostic
The battery of diagnostic product
The date of diagnostics
The working situation of diagnostic product
Number of schistosomiasis eggs
Amount of urine
PH (acid) of urine
Color of urine
Red/ white blood cell in urine
Pregnancy of patient
Age of patient
Occupation of patient
Frequency in health check
Salary/ income of the patient
The contact information of the patient
Gender of patient
Family medical history
The heart rate of patient
Residential location
Working location
Frustrations
Number of staff member
Position of staff member
Adcive
Insurance or not. → payment method.
Travel history.
diet (vege / meat) → nutrition status.
Blood history → assist diagnostic.
Sensor
System
Diagnosis result
Fill in forms
Expression
Global, worldwide
Non-profit Orginization
Govermental
Private companies
About children
About health
About ecnonmy
About research
vital sign
BP
HR
RR
Blood Rate
Heart Rate
Rate
who
why
- UNICEF
People to touch upon
Location of residence
Population of kids
Facilities monitor & maintain
Weather & climate change
Water hygiene situation
Children abuse & labor
Frequency of screening
- WHO
Health coverage
Essential health product coverage
Prepare for health emergency
Identify / manage health emergency
Support health service in fragile settings
General health & wellbeing
Prioritize & promote health in policies
Eliminate high-impact disease
Global observatory of data (VHO)
Data monitoring & information
- World Bank
Understanding a country's economic situation
Support disease defending
- Ministry of Health
Health Coverage
MDA MASS drug administration
Health & wellbeing of citizen
Control andelimination program
Rapid mapping
- Primary Health care
Citizen's life cycle health planning and management
Infrustructionassessments (Facility / workers training)
Quality / guidline approval of programs
Disease control program
- Local Clinic
National and International pharmacy practice adherency
Pharmacists registration
- DataFirst
database settings
numbers calculation
- dLab
database settings
numbers calculation
- Health Entrepreneurs
Governmental relationship maintain
Distant doctors program
Monitoring needs
Stock ordering / estimation
Micro-entrepreneurs traiaing
- Smart Medical Optics
Understand the effectiveness of diagnostic advice
Seak potential technology development
- Medical/ Health suppliers
Keep up with regulations
Maintian need / supply


DATA CAPTURING
VALUE CREATION
BENEFICIAL STAKEHOLDER
where (data about...)
how (data via...)
what
who
why
location
device
disease
patients
medical staff
diagnostic device
diagnostic result
patients
medical staff
Location of diagnostic
Temperature of diagnostic
Humidity of diagnostic
The battery of diagnostic product
The date of diagnostics
The working situation of diagnostic product
Number of schistosomiasis eggs
Amount of urine
PH (acid) of urine
Color of urine
Red/ white blood cell in urine
Pregnancy of patient
Age of patient
Occupation of patient
Frequency in health check
Salary/ income of the patient
The contact information of the patient
Gender of patient
Family medical history
The heart rate of patient
Residential location
Working location
Frustrations
Number of staff member
Position of staff member
Adcive
UNICEF
People to touch upon
Location of residence
Population of kids
Facilities monitor & maintain
Weather & climate change
Water hygiene situation
Children abuse & labor
Frequency of screening
WHO
Health coverage
Essential health product coverage
Prepare for health emergency
Identify / manage health emergency
Support health service in fragile settings
General health & wellbeing
Prioritize & promote health in policies
Eliminate high-impact disease
Global observatory of data (VHO)
Data monitoring & information
World Bank
Understanding a country's economic situation
Support disease defending
Ministry of Health
Health Coverage
MDA MASS drug administration
Health & wellbeing of citizen
Control andelimination program
Rapid mapping
Primary Health care
Citizen's life cycle health planning and management
Infrustructionassessments (Facility / workers training)
Quality / guidline approval of programs
Disease control program
Local Clinic
National and International pharmacy practice adherency
Pharmacists registration
DataFirst
database settings
numbers calculation
dLab
database settings
numbers calculation
Health Entrepreneurs
Governmental relationship maintain
Distant doctors program
Monitoring needs
Stock ordering / estimation
Micro-entrepreneurs traiaing
Smart Medical Optics
Understand the effectiveness of diagnostic advice
Seak potential technology development
Medical/ Health suppliers
Keep up with regulations
Maintian need / supply

Stakeholders in the field:

1 Medical research institution - LUMC
Parasite and Infections disease study
Medicine, drugs, and vaccines development
Biomedical and biotechnology study
Diagnostic tools development
Prevention study
Specialist training and education
2 Medical staff - xxx
Medication monitoring and administering
Surgery performing
Diagnostic and treatment performing
Record and report maintaining
Patient care providing
3 Frontline health workers (FLHWs) - HE
Adhere to policies and higher level behavior
Community serving
Link creation between local context and health systems
Bringing Health solution in practice
Immunization providing
4 Data analytics company - xxx
Database setting
mass data value Leveraging
Artificial intelligence and machine learning improvement
Analytics tool advancing
Client decision-making assist
Market opportunities Exploring
5 Global health control organization - WHO
Health coverage promotion
Health emergency preparing
Prioritizing and promoting health in policies
Disease elimination study
Data monitoring
Health-related global action planning
6 Medication supply company - Smart Optics
Technology study and exploring
low-cost and sensitive diagnostic instruments designing
Diagnostic method studying
Medical equipment providing
Deploying low resource setting markets
7 Governmental and national level - xxx
Infrastructure assessing
Quality and guideline approving
Citizen health cycle planning
National and international goal adhering
Disease defending strategy planning
Drug and supply distributing

Data around disease controling:



Phases for disease controling:

Census	Disagnostic	Treatment	Report	Strategy Planning	Training	Prevention / Education	Monitoring

global ORGs.
International RESEARCH C..
International SUPPLY CO.
national HEALTH (or related) MINISTRY
regional / local FACILITIES
local CITIZENs

Global Disease Elimination Program
Disease Research Center
Diagnostic Device Design Company
Country level Health ministry
Medical staff
Health-related Facilities
Frontline Health workers
Citizens with symptoms
General Citizen

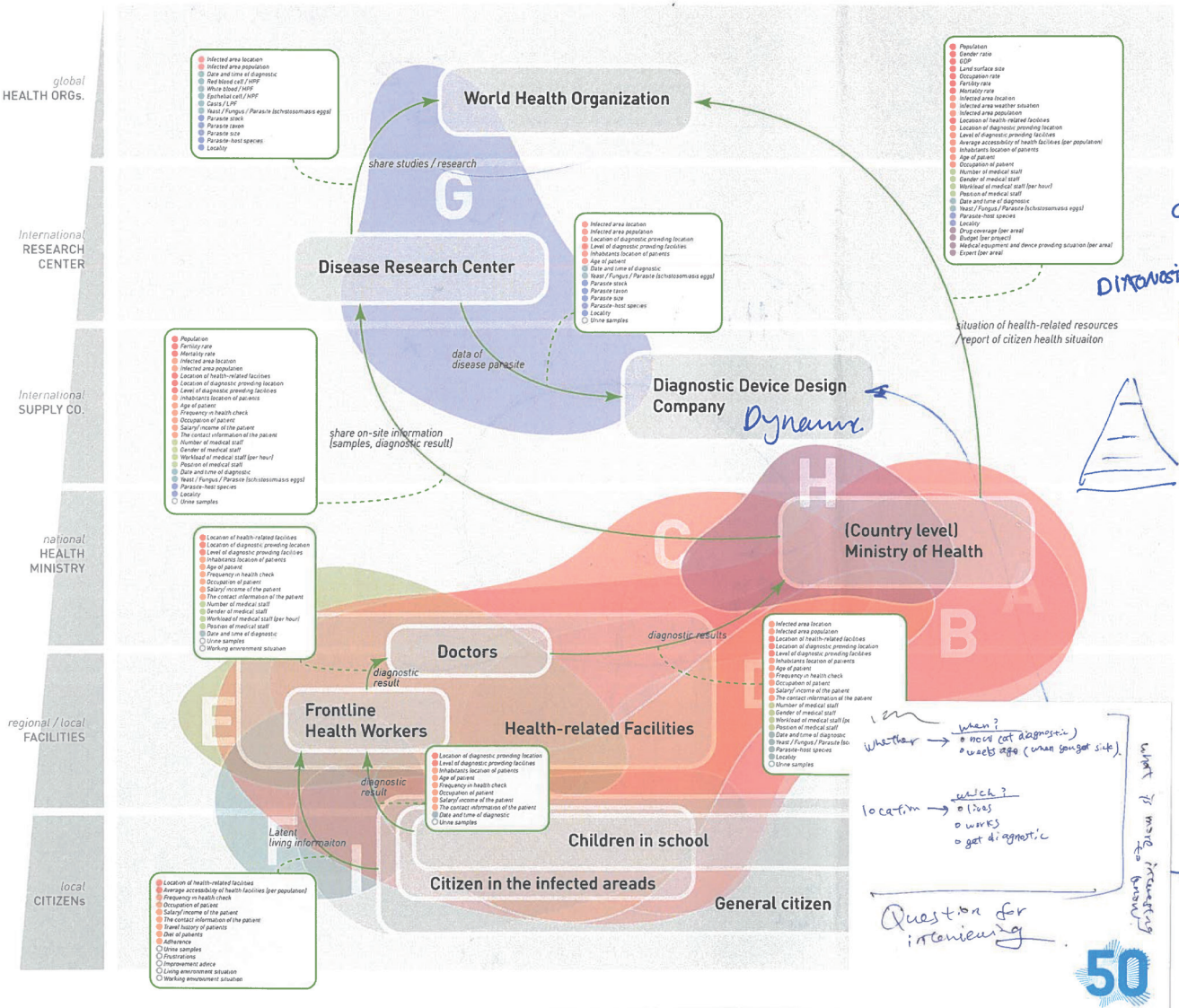
SUPPORTING/ COLLABORATING
REPORT
PROVIDE COLLECTED INFORMATION
SEAK EXPERT KNOWLEDGE
ADVICE FOR IMPROVEMENT
SUPPORTING
REPORT
ADVICE FOR DIAGNOSTIC
ASK FOR FIRST HANDED INFORMATION
LOOK FOR MARKET OPPORTUNITIES
PROVIDE DEVICE
REPORT
LOOK FOR FIRST HANDED INFORMATION
ASK FOR ASSIST
RESOURCES
SUPPORTING
DIRECTIONS FOR IMPROVEMENT
SUPPORTING
TREATMENT TO IMPROVE HEALTH
DISCOVER NEEDS
ASK FOR DIAGNOSTIC

Information direction
Information requesting direction
Supporting direction
Advice direction

What data is transferred

- request
- Just asking
- transfer of information (or data)
- " " resources

Medical sans frontier



A. Country related data
a. Population
b. Gender ratio
c. GDP
d. Land surface size
e. Occupation rate
f. Fertility rate
g. Mortality rate
h. Migration rate
i. Literacy rate
j. Exploitation rate

B. Content related data
a. Infected area location
b. Infected area weather situation
c. Infected area population

C. Facilities related data
a. Location of health-related facilities
b. Location of diagnostic providing location
c. Level of diagnostic providing facilities
d. Average accessibility of health facilities (per population)

D. Citizen / Patient-related data
a. Inhabitants location of patients
b. Age of patient
c. Frequency in health check
d. Occupation of patient
e. Salary/ income of the patient
f. The contact information of the patient
g. Travel history of patients
h. Diet of patients
i. Adherence

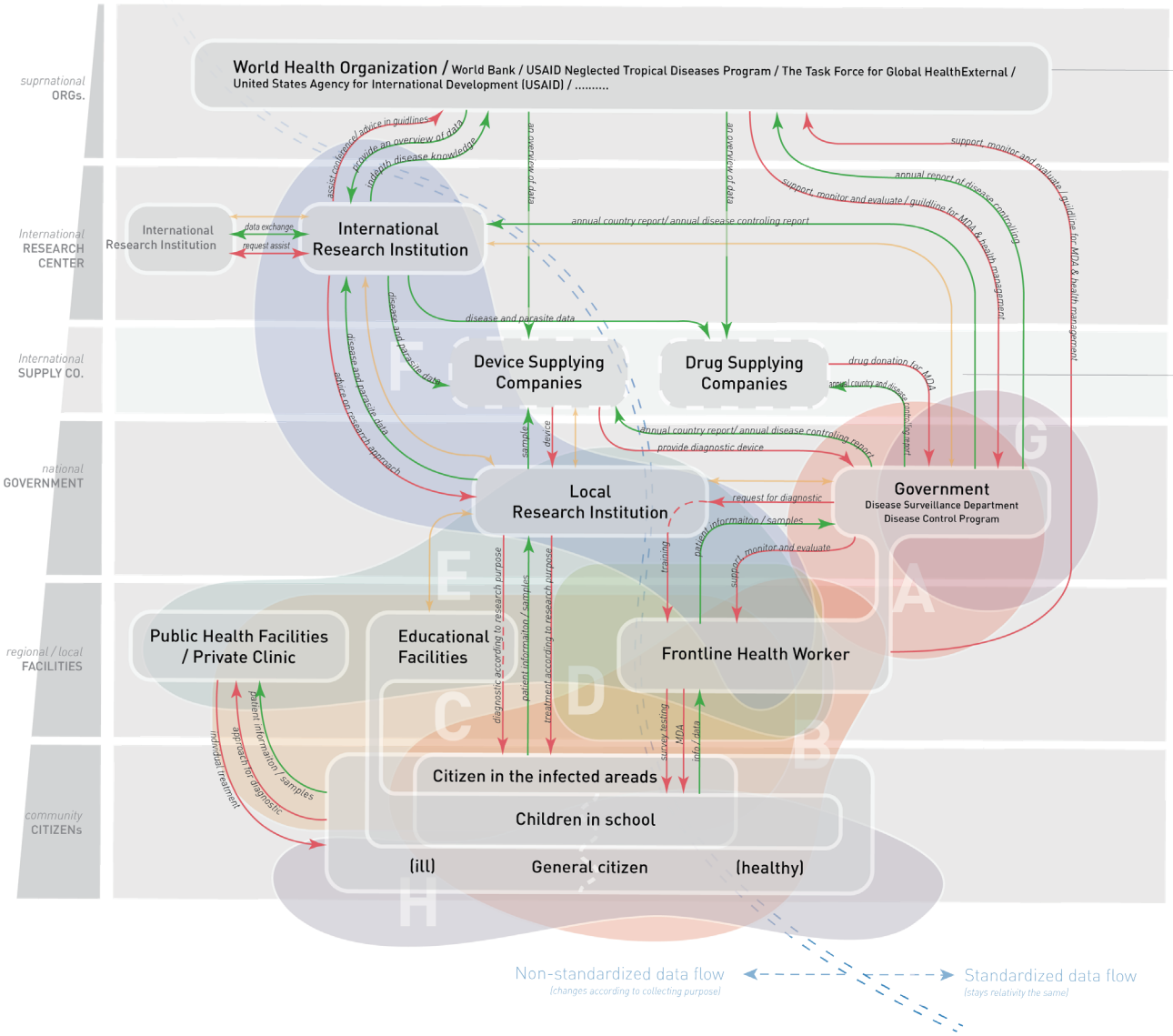
E. Medical staff related data
a. Number of medical staff
b. Gender of medical staff
c. Workload of medical staff (per hour)
d. Position of medical staff

F. Diagnostic result related data
a. Date and time of diagnostic
b. Amount of urine (per day)
c. Appearance of urine
d. Specific gravity (hydration / kidney illness)
e. Glucose of urine (Diabetes / kidney illness)
f. Protein of urine (High blood pressure / kidney illness)
g. Bilirubin (liver illness)
h. PH (acid) of urine
i. Nitrite of urine (infection)
j. Color of urine
k. Occult blood of urine (urinary system problem / Rhabdomyolysis)
l. Red blood cell / HPF
m. White blood / HPF
n. Epithelial cell / HPF
o. Casts / LPF
p. HCG of urine (Pregnancy)
q. Urine cytology (Cancer)
r. Yeast / Fungus / Parasite (schistosomiasis eggs)

G. Parasite related data
a. Parasite stock
b. Parasite taxon
c. Parasite size
d. Parasite-host species
e. Locality

H. Resources related data
a. Drug coverage (per area)
b. Budget (per project)
c. Medical equipment and device providing situation (per area)
d. Expert (per area)

I. Other (qualitative) data
a. Urine samples
b. Frustrations
c. Improvement advice
d. Living environment situation
e. Working environment situation



https://www.cdc.gov/global-health/ntd/resources_publications/index.html

https://www.neglecteddiseases.gov/about/drug-donation-partnership

List of related data:

- dynamic data (measure / capture)
- static data (request / collect)

A. Country related data (national data)
- a. Population
- b. Gender ratio
- c. GDP
- d. Land surface size
- e. Occupation rate
- f. Fertility rate
- g. Mortality rate
- h. Migration rate
- i. Literacy rate
- j. Exploitation rate

B. Infected area related data (regional / state data)
- a. Infected area location
- b. Infected area weather condition
- c. Infected area population
- d. Location of health-related facilities
- e. Average accessibility of health facilities (per population)

C. Citizen / Patient-related data
- a. Inhabitants location of patients
- b. Age of patient
- c. Frequency in health check
- d. Occupation of patient
- e. Salary/ income of the patient
- f. The contact information of the patient
- g. Travel history of patients
- h. Diet of patients
- i. Adherence

D. Medical staff related data
- a. Number of medical staff
- b. Gender of medical staff
- c. Workload of medical staff (per hour)
- d. Position of medical staff

E. Diagnostic result related data
- a. Urine samples
- b. Location of diagnostic providing location
- c. Level of diagnostic providing facilities
- b. Date and time of diagnostic
- e. Amount of urine (per day)
- f. Appearance of urine
- g. Specific gravity (hydration / kidney illness)
- h. Glucose of urine (Diabetes / kidney illness)
- i. Protein of urine (High blood pressure / kidney illness)
- j. Bilirubin (liver illness)
- k. PH (acid) of urine
- l. Nitrite of urine (infection)
- m.Color of urine
- n. Occult blood of urine (urinary system problem / Rhabdomyolysis)
- o. Red blood cell / HPF
- p. White blood / HPF
- q. Epithelial cell / HPF
- r. Casts / LPF
- s. HCG of urine (Pregnancy)
- t. Urine cytology (Cancer)
- u. Yeast / Fungus / Parasite (schistosomiasis eggs)

F. Parasite related data
- a. Parasite prevalence
- b. Parasite taxon
- c. Parasite size
- d. Parasite-host species
- e. Parasite FOI (force of infection)
- f. Parasite antigens (CAA, CCA)
- g. Locality

G. Resources related data
- a. Drug coverage (per area)
- b. Budget (per project)
- c. Medical equipment and device providing situation (per area)
- d. Expert (per area)

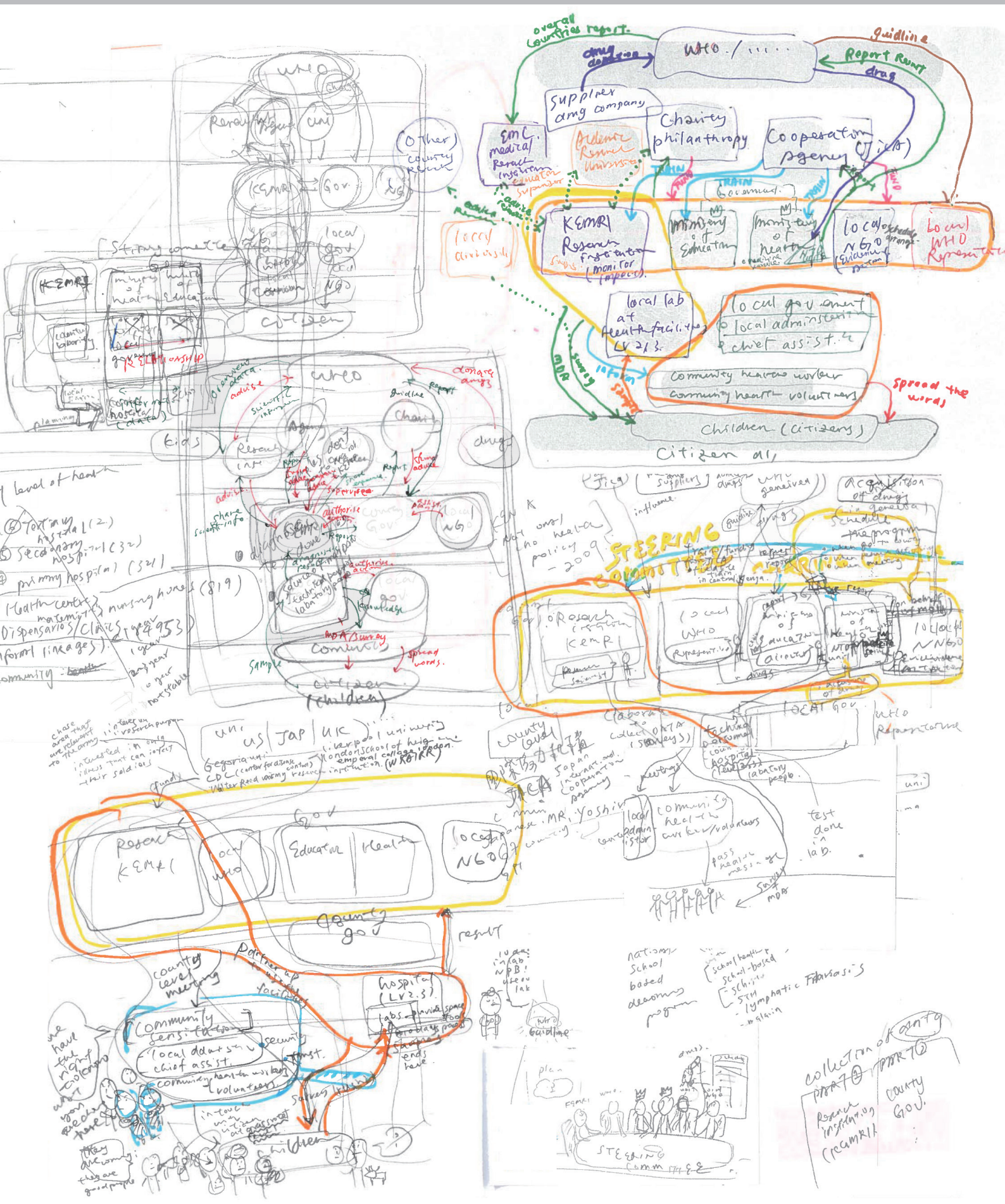
H.Other (qualitative) data
- a. Frustrations
- b. Improvement advice
- c. Living environment situation
- d. Working environment situation

Area where the data source can be found:

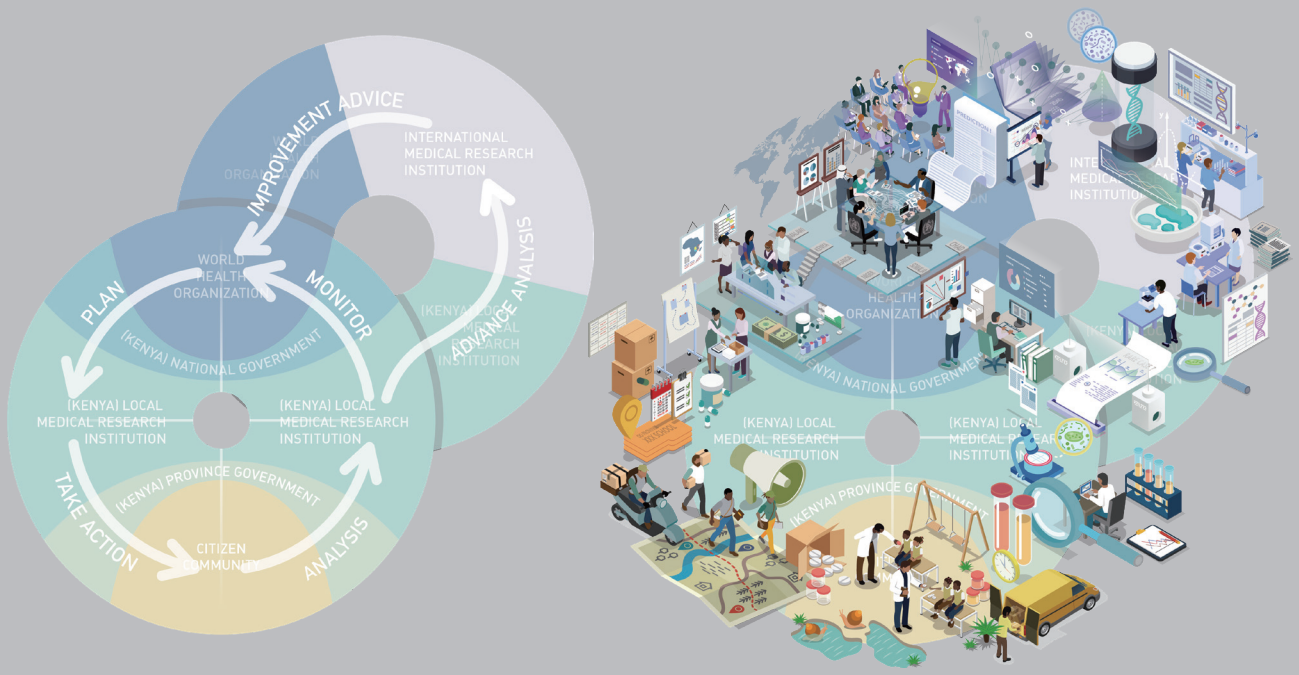
- A. Country related data
- B. Infected area related data
- C. Citizen / Patient-related data
- D. Medical staff related data
- E. Diagnostic result related data
- F. Parasite related data
- G. Resources related data
- H. Other (qualitative) data

Relationship between players:

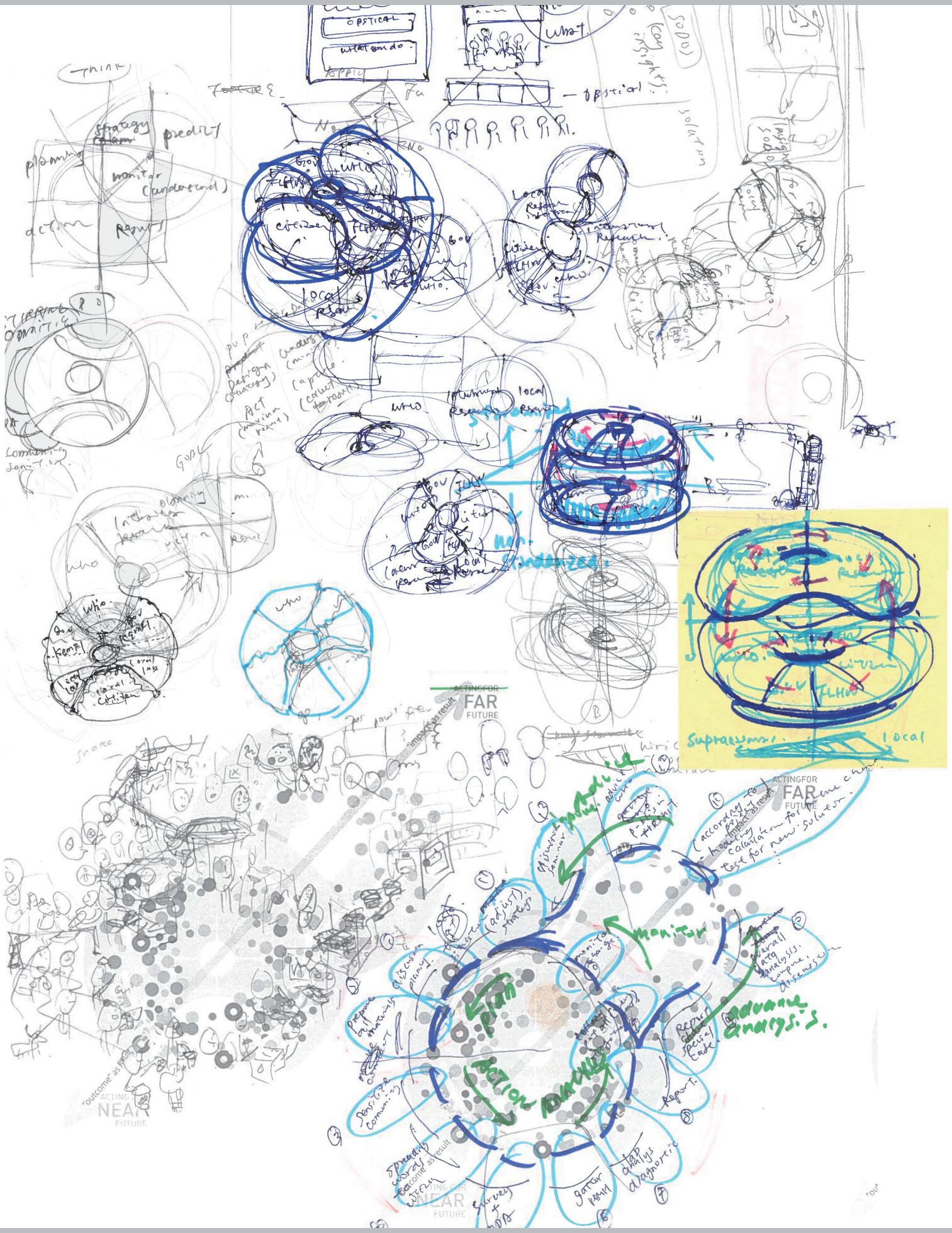
- Data / Information flowing direction
- Action direction
- Collaboration


overal countries report
WHO
Guidline
Report Resort
drug
supplier
drug company
Charity
philanthropy
Cooperation
agency
EMC
medical
Research
Guidline
KEMRI
Research
Ministry
of
Education
local
NGO
local WHO
Representative
local lab
at
Health facility
LV 2/3
local government
local administrative
chief assist.
community health worker
community health volunteers
spread the
words
Children (citizens)
Citizen all
STEERING
COMMITTEE
Research
KEMRI
local
WHO
Representative
Education
Health
local
NGO
county
level
meeting
hospital
(LV 2.3)
community
sensitization
local administrative
chief assist.
community health workers
volunteers
Children
Research
KEMRI
local
WHO
Education
Health
local
NGO
county
gov
result
STEERING
COMMITTEE

Result: (see Figure 3-4, 4-3)



Progress:


THINK
strategy
predict
plan
monitor
understand
act
result
OPTICAL
what do
what
who
local
global
Supranational
ACTINGFOR
FAR
FUTURE
monitor
plan
action
analysis
ACTINGFOR
NEAR
FUTURE

E. Blank mapping sheet

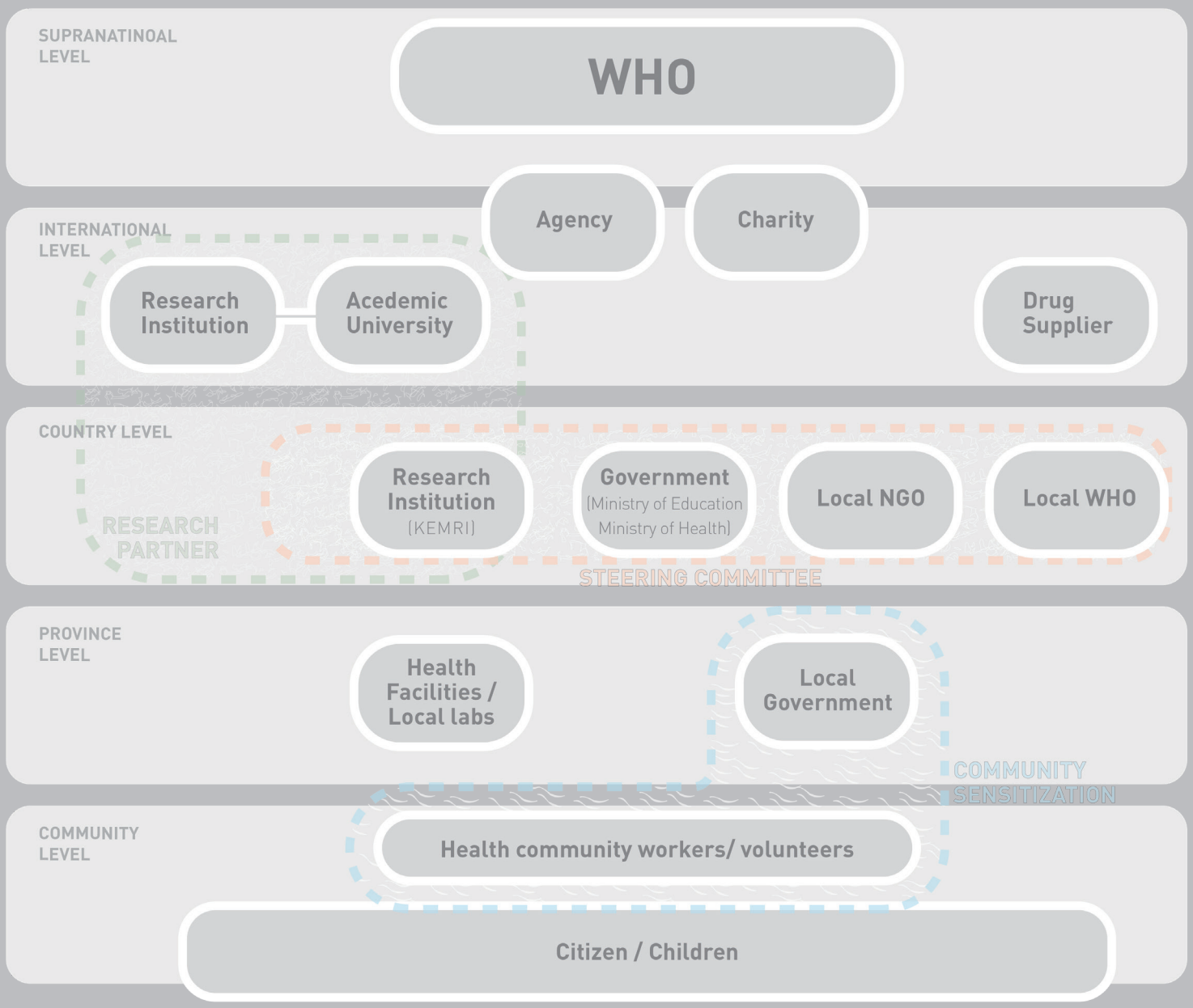
SUPRANATINOAL
LEVEL

INTERNATIONAL
LEVEL

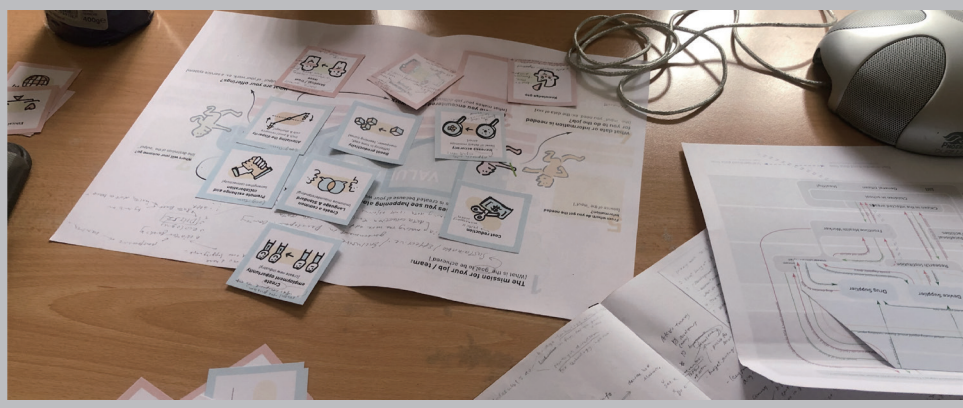
COUNTRY LEVEL

PROVINCE
LEVEL

COMMUNITY
LEVEL


SUPRANATINOAL LEVEL
WHO
Agency
Charity
INTERNATIONAL LEVEL
Research Institution
Acedemic University
Drug Supplier
COUNTRY LEVEL
RESEARCH PARTNER
Research Institution (KEMRI)
Government (Ministry of Education Ministry of Health)
Local NGO
Local WHO
STEERING COMMITTEE
PROVINCE LEVEL
Health Facilities / Local labs
Local Government
COMMUNITY SENSITIZATION
COMMUNITY LEVEL
Health community workers/ volunteers
Citizen / Children

MEDECINS SANS FRONTIERES
DOCTORS WITHOUT BORDERS



Diagnostic result related data
Parasite related data

KENYA MEDICAL RESEARCH INSTITUTE

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Vision
To be a leading centre of excellence in research for human health.
Mission
To improve human health and quality of life through research, capacity building, innovation and service delivery
STOP
SPEED LIMIT 10 KPH

MRI for Low Resources

amref health africa
RECEPTION
AMREF KCO
VISITOR
PASS NUMBER
028
Please surrender this Pass to the Security desk on leaving the premises
amref Lasting health

Nairobi Innovation Week
UNIVERSITY OF NAIROBI
MAKER SPACE

Insure Now!

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